

# **Parents' Use of Social Media for Health Information: An Australian Mixed Methods Study**

By

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Thesis submitted in fulfilment of the requirements for the degree

Doctor of Philosophy

under the supervision of

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## Certificate of Original Authorship

I, Erika Frey, declare that this thesis is submitted in fulfilment of the requirements for the award of Doctor of Philosophy in the School of Public Health, Faculty of Health at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise referenced or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

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Signature:

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## Publications Incorporated into this Thesis

This thesis by compilation contains seven chapters, four of which are manuscripts; Chapters 2 and 4 are published manuscripts. Chapters 5 and 6 are under review. Manuscript details for each chapter are outlined below with percentage contributions for each author.

### Incorporated as Chapter 2

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Statement of Contribution	Percentage of contribution
Concept and design of the study	EF 70% CB, MB, JF 30%
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Data analysis and interpretation	EF 70% CB, MB, JF 30%
Writing of initial manuscript	EF 70% CB, MB, JF 30%
Manuscript revision and editing	EF 70% CB, MB, JF 30%

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## Presentations

During my candidature, I presented at one conference.

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## Abbreviations

95%CI	95% Confidence Interval
ABS	Australian Bureau of Statistics
ADHD	Attention Deficit Hyperactivity Disorder
ADIA	Australian Data and Insights Association
AIHW	Australian Institute of Health and Welfare
ALLS	Adult Literacy and Life Skills Survey
ASAP	As Soon As Possible
ASD	Autism Spectrum Disorder
AUD	Australian Dollar
CDBS	Child Dental Benefits Schedule
CINAHL	Cumulated Index to Nursing and Allied Health Literature
COVID-19	Corona Virus Disease 2019
CTDS	Critical Thinking Disposition Scale
CTDS_CO	Critical Thinking Disposition Scale: Critical Openness
CTDS_RS	Critical Thinking Disposition Scale: Reflective Scepticism
ECR	Early Career Researcher
GP	General Practitioner
HCP	Healthcare Professional
HDR	Higher Degree by Research
HPV	Human Papilloma Virus
HREC	Human Research Ethics Committee
IBM	International Business Machines
IF	Impact Factor
IRSAD	Index of Relative Socio-Economic Advantage and Disadvantage
ISO20252	International Organisation for Standardisation document 20252
JBI	Joanna Briggs Institute
JMIR	Journal of Medical Internet Research
Kg	Kilograms
LHD	Local Health District
mL	Millilitres
Mths	Months
n=	Number of
NHMRC	National Health and Medical Research Council
NHS	National Health Survey
NIH	National Institute of Health (US)
NIP	National Immunisation Program
NNAPS	National Nutrition Physical Activity Survey
NSW	New South Wales

OR	Odds Ratio
ORCID	Open Researcher and Contributor Identification
OT	Occupational Therapist
P	P value (0.05)
P1-19	Participant 1-19
PBS	Pharmaceutical Benefits Scheme
PIS	Participant Information Sheet
PND/PPD	Post Natal Depression/Post-Partum Depression
PPSI	Parenting Plus Skills Index
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PRISMA-ScR	Preferred Reporting Items for Systematic Reviews and Meta-Analyses-Scoping Review Extension
Q1	1 <sup>st</sup> Quartile (top)
Q2	2 <sup>nd</sup> Quartile
Q3	3 <sup>rd</sup> Quartile
Q4	4 <sup>th</sup> Quartile (bottom)
QOR	Quality Online Research
QR code/link	Quick Response code/link
qual	Qualitative Research (non-dominant)
QUAN	Quantitative Research (dominant)
RQ	Research Question
SCID	Severe Combined Immune Deficiency
SCT	Social Cognitive Theory
SEIFA	Socio-Economic Index of Areas
SIDS	Sudden Infant Death Syndrome
SPSS	Statistical Package for Social Sciences
STROBE	Strengthening Reporting of Observational Studies in Epidemiology
TA	Thematic Analysis
TRD	Triadic Reciprocal Determinism
TV	Television
UGC	User Generated Content
UK	United Kingdom
US	United States
USD	United States Dollar
UTS	University of Technology Sydney
Yrs	Years

## Summary

### **Aim:**

This doctoral research project explores Australian parents' use of social media for health information for their children. This thesis aims to explore the prevalence of social media use by parents for health information as well as the characteristics and determinants of this use, including health literacy and critical thinking. This thesis will also investigate how parents use social media to find health information for their children, including platforms accessed and how this use intersects with health professional visits.

### **Method:**

A convergent mixed methods research design was used, including a scoping review, a nationally representative survey of 1000 Australian parents stratified by gender and state, and semi-structured interviews of parents (n=19).

### **Results:**

The majority (82.2%) of Australian parents of children aged 6 months to 5 years that use social media, use it to access health information for their children. Parents aged between 30 and 39 and born in Australia are most likely to use social media for health information. Parents of children of all ages use social media for support and insights based on other parents' lived experience and information. A direct inverse relationship between parents' health literacy and their use of social media for health information was observed.

### **Conclusion:**

The majority of Australian parents use social media to seek health information for their children. Given the variable quality of health information on social media, research to improve parental health literacy and reduce dependence on social media for health information is warranted.

## Chapter 1 – Introduction

This thesis explores the phenomenon of parents' use of social media for health information for their children. Social media has changed the overall health information landscape, specifically as we will investigate in this research. There are many reasons parents use social media for health information, including the easy accessibility and convenience it allows, the ability to access information based on the lived experience of other parents who are experiencing the same health queries or journey, and the sense of community that it creates amongst users that is not able to be facilitated geographically. The Australian parents' experience of social media isn't known to date – their characteristics, motivations and sentiments, but also their personal lived experience of doing so. This thesis aims to gain an understanding of this phenomenon within the Australian context and answer these questions.

This chapter provides the author's positioning statement of how she came to research how parents use social media for health information. This is followed by an overview of the Australian health system, the health status of children in Australia, and descriptive statistics about families in Australia. The evolution of social media is then briefly discussed. Following this, the project aims, objectives, research questions and significance and scope are described. The chapter ends with an overview of the structure of this thesis.

### 1.1 Author's Positioning Statement

I came to this area of research through my own lived experience, both in a professional capacity and as a new parent myself. By 2015, I had graduated with a medical science degree and was halfway through a Master of Pharmacy. Before taking maternity leave from my course in 2014, I had completed many hours of placement in different pharmacies across Sydney. At the time, I noticed something consistent across all demographics and all locations. Parents of children generally don't always have the health knowledge or health literacy to rely on as far as what they should do when their child is 'just not right'. This really came to the fore in my mind after becoming a parent

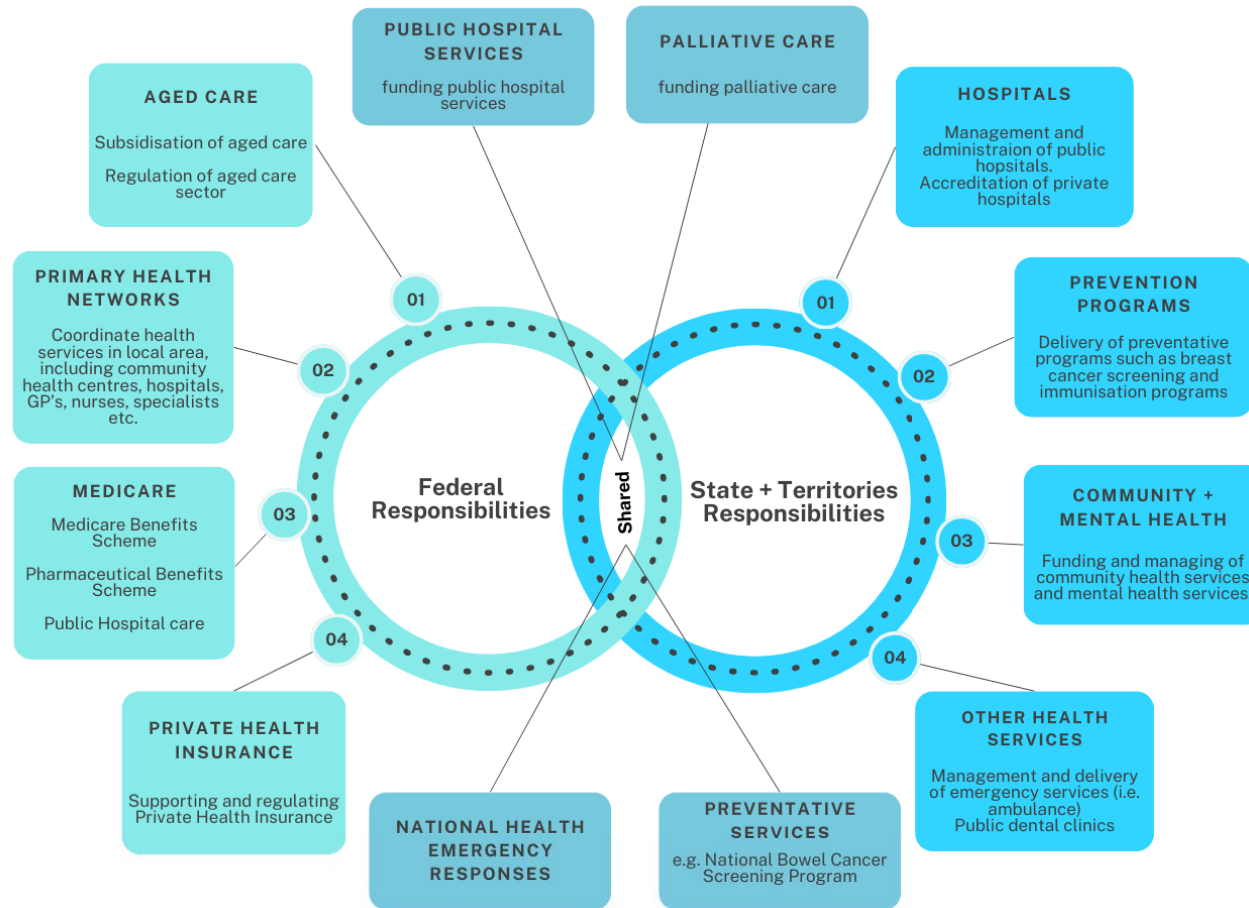
myself. I really knew that these parents were trying their best, just as I was, and all they wanted was to do what was best for their child, but they didn't always know where to start. I also started to see a shift in social media, with parents asking each other for health information for their children. Some of it was of low consequence, things like recommendations for the best throat lozenges that a 6-year-old would tolerate. But I also saw some situations where children, from what was described, were clearly unwell, but the parents didn't know what to do, and were reaching out on social media trying to work out their next steps. Every time I saw this happen, which in one form or another was on a daily basis, I could not help but wonder – *why do (Australian) parents use social media for health information?* It is this question and my research to find the answer that has driven and resulted in this thesis.

## 1.2 The Australian Health System

The Australian health system is run by all levels of government (federal, state and territories, and local) to provide Australians with safe, quality, and affordable healthcare (Figure 1.1). In 1984, Australia established its universal health insurance scheme called Medicare. Medicare is funded by taxpayers with general tax revenue (Australian Taxation Office, 2023) with an additional Medicare Levy Surcharge for those earning more than \$93,000 for singles or \$186,000 for couples who do not hold appropriate private health insurance coverage (Australian Taxation Office, 2023). Medicare, via the Medicare Benefits Scheme (MBS), funds all public hospital care. It also can pay, with no gap payment by bulk-billing or subsidise (leaving a gap payment) the cost of consultations with private specialists if referred by a General Practitioner (GP). Medicare also subsidises pharmaceuticals through the Pharmaceutical Benefits Scheme (PBS), ensuring that Australians have equitable access to evidence-based, life-saving medications when needed (Australian Government Department of Health and Aged Care, 2024a). The MBS also covers maternity services provided through public hospitals at minimal or no cost to help ensure that parents have access to vital care during pregnancy, childbirth and the postpartum period (Services Australia, 2023b).

The Australian Government also funds programs in collaboration with the State and Territory governments that roll out federally funded programs to ensure timely access to every Australian (Australian Government Department of Health and Aged Care, 2023c). One such program is the National Immunisation Program (NIP) (Australian Government Department of Health and Aged Care, 2023b). The NIP outlines the Australian children's immunisation schedule, which is benchmarked at ages 1, 2, and 5 to determine if children are up to date (i.e. “fully immunised”) and have received all immunisations as outlined in the NIP. In 2022, 92% of Australian 2-year-old children were fully immunised, slightly lower than 1-year-olds and 5-year-olds, both at 94%, reflecting the changes made to the NIP Schedule in December 2014 and March 2017 (Australian Government Department of Health and Aged Care, 2023a).

Figure 1.1 The Australian Health System [snapshot overview]



### 1.2.1 State and Territory Health Systems

State and Territory Governments fund and deliver aspects of the health system for their specific state or territory, including public community-based and primary care services (e.g. dental care, mental health, drug and alcohol services) and ambulance services. State and territory governments also regulate parts of the health system, including the licencing of private hospitals and the handling of health complaints, as well as managing the public hospitals in their state or territory (Australian Institute of Health and Welfare, 2022b). Within NSW, there are 17 Local Health Districts (LHDs), consisting of six LHDs covering Greater Sydney and seven covering rural and regional NSW. There are also two specialist networks- one for paediatric services and one for justice health and forensic mental health. St Vincent's Network is an affiliated health organisation that operates as a third network in NSW (NSW Health, 2023b). For very specialised services that are only available in selected facilities, there are Supra-LHD service agreements where patients are able to access the service they need anywhere in NSW there is a bed available – for example, the Severe Burns Service at Concord Hospital (Sydney LHD) or the Hyperbaric Medicine Unit at Prince of Wales Hospital (South Eastern Sydney Local Health District) (NSW Health, 2023a). These Local Health Districts and networks are responsible for delivering the majority of public health services to NSW residents within their Local Health District (NSW Health, 2020).

## 1.3 Primary Health Care

There are 31 Primary Health Networks in Australia. These networks coordinate the health services in local areas to improve patient care. They are also involved in coordinating the various parts of the health system and providing the extra services needed in their local area (Australian Government Department of Health and Aged Care, 2023b).

General Practitioners (GPs) are often the first point of contact for those seeking healthcare in Australia (Australian Institute of Health and Welfare, 2023a). They are also the main point of access to the broader health system for maximum efficiency (Clarke, 2021). There were approximately 154 million GP attendances recorded in



2019-2020 (Australian Institute of Health and Welfare, 2022b), with the services provided being fundamental to the overall health of Australians, particularly for routine and preventative care as well as the management of chronic conditions (Royal Australian College of General Practitioners, 2023). Primary health care can also be provided by nurses, nurse practitioners, pharmacists, allied health professionals, midwives, dentists, and Aboriginal and Torres Strait Islander health workers (Australian Institute of Health and Welfare, 2016).

## 1.4 Private Health Insurance

Private health insurance is available and regulated by the federal government in Australia, providing those with an appropriate level of coverage, the choice of specialists and hospitals. Those with coverage are also able to have non-urgent medical issues attended to more promptly (in most cases) by being able to avoid the public waiting list for medical care (Biggs, 2016) as a private patient. There are often out-of-pocket expenses that the patient needs to self-fund when using private health insurance with private healthcare.

## 1.5 Challenges within the Australian Health System

The Australian healthcare system is under strain, including difficulties with a persistent lack of adequate labour force (Australian Medical Association, 2021), long public list waiting times and increasing costs involved in healthcare (Australian Government Department of Health and Aged Care, 2018). These factors, alongside Australia's vast landscape (Nolan-Isles et al., 2021), access to healthcare across Australia isn't optimal, nor is it equitable, leading some Australians to forgo their required healthcare (Biggs, 2016).

### 1.5.1 Lack of labour force in regional, rural and remote Australia

Australia's geography presents a major challenge to equitable access to healthcare for all Australians. With 87% of Australians living within 50km of the seaboard (Commonwealth of Australia (Australia State of the Environment) 2021), those who

live away from the concentrations of population in cities or towns can have difficulty with physical access to the health services they need (Baxter, 2011). For the health workforce, being able to train and recruit health workers with the intention of retaining them in rural and regional locations has proven to be difficult for a variety of reasons. While the evidence suggests that those who were born and raised in rural locations are more likely to return to them once they have finished their training (Lyle et al., 2007), this strategy alone has been not sufficient to meet the demand. There are a number of reforms that past governments have implemented to varying degrees of success (Phillips, 2019).

In a recent perspective piece for the Medical Journal of Australia (Murray & Craig, 2023), it was suggested that to meet the need for junior doctors in rural, regional and remote areas of Australia, up to 3000 doctors were needed to enter the Australian medical workforce annually – a similar number to the medical students that graduate every year. Compounding this is the significant issue of the city-centric nature of both a doctor’s post-university training and subsequent career in many areas of medicine (World Health Organization., 2020), keeping many doctors in the population-dense areas away from the rural, remote and regional areas of Australia. As a result, many people who live in rural, regional and remote areas are underserved by the medical and health services they need and subsequently have higher rates of morbidity and mortality than those who live in the cities (Gunn et al., 2020).

### 1.5.2 Long waiting lists

Access to timely health care is a widespread concern and issue for the whole of Australia’s population. A current example is that of specialist care from paediatricians (Mulraney et al., 2021), whose expertise is needed to diagnose and treat neurodevelopmental conditions such as Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD) in children. The issue has become so apparent that it has been consistently covered in the mainstream media, with one recent report highlighting parents who haven’t been able to access paediatricians at all in their home state (Western Australia) and have been required to fly interstate to get

the care needed for their child, despite the waitlists for private paediatric care being months and years long elsewhere in Australia (Dow, 2024).

Not every state makes available their public outpatient waiting list times, such is the case for NSW, but in Tasmania, for example, the waitlist is 3 years to see a developmental paediatrician in a public clinic (thereby reducing the costs of seeking treatment by being bulk-billed with no gap payment) (Tasmania Health, 2023). Allied health, which has been shown to be integral to improved patient outcomes (Lizarondo et al., 2015), also has long waitlists (McGill et al., 2020), leading to delays in supportive and interventional therapies. For many children, this is too long in their formative years, leading to possible life-long consequences and deficits as a result of missing out on timely diagnosis, treatment and early intervention (Landa, 2008).

### 1.5.3 Increased costs involved with healthcare

Out-of-pocket costs have been increasing for GPs and private paediatrician consultations, despite being subsidised by Australia's universal health insurance scheme, Medicare (cleanbill, 2024). In the year between 2023 and 2024, Australia-wide, there were 11.1% fewer General Practice clinics that bulk-bill, while out-of-pocket expenses increased by 3.1%. In NSW, there are 11.4% fewer bulk-billing clinics than in 2023, with the out-of-pocket expenses increasing by 3.1% to an average of \$42.37 (cleanbill, 2024). Western Australia had the biggest change, with a 16.9% reduction in bulk-billing clinics between 2023 and 2024. Tasmania had the largest average increase in out-of-pocket costs, with an increase of 8.5% to \$51.67 between 2023 and 2024 (cleanbill, 2024).

In November 2023, the Australian federal government brought about incentives to increase bulk-billing by GPs for priority groups, including children (Australian Government Department of Health and Aged Care, 2024b). While there were incentives previously for children, these new incentives saw a tripling of payment to GPs to bulk-bill children – up from \$6.85 to \$20.65 in metropolitan areas and \$39.65 in remote areas, up from \$13.15 (Attwooll, 2024). This would be payable in addition to the scheduled fee that the doctor would receive for the services provided, which for a

standard consultation that is more than 6 minutes and less than 20 minutes (item 23) is \$41.40 (Medicare Australia, 2024).

Costs for paediatric medicine have been increasing, both for the system and the patient. In 2020-2021, there were 1.3 million paediatric medicine services provided to 2.3% of Australia's population, being the 8<sup>th</sup> most in-demand specialisation in Australia by number of attendances. For non-hospital (i.e. private outpatient consultations) referred medical specialisations, paediatric medicine was the 4<sup>th</sup> highest by Government spending, with paediatric medicine costing the system \$160.9 million.

For patients the out-of-pocket cost to see a paediatrician has been steadily increasing also. A 2017 study (Kunin et al., 2017) found that the average out-of-pocket expense for a consultation at the time with a private paediatrician in Melbourne was \$128 (range \$40 - \$222). In 2021-2022, the average out-of-pocket expense across Australia had risen to \$153 (range \$53 – \$313). New South Wales had an average out-of-pocket of \$148, while Western Australia had the highest out-of-pocket at \$258 (Department of Health and Aged Care, 2024).

## 1.6 The Australian Health System for Children

In addition to being automatically enrolled into Medicare when a child's birth is registered (Services Australia, 2023a), both the federal and state health systems have specific programs and funding for child-centred health initiatives and programs. An example of these programs include:

### **Federally funded programs**

1. The Child Dental Benefits Schedule (CBDS) is a federally funded scheme for children of low-income families to receive subsidised regular dental check-ups and basic dental services (e.g. Fillings). This initiative aims to promote good oral hygiene practice from an early age and assist families in accessing dental services through the private system in a timely manner (Services Australia, 2022).

2. **School Health Programs:** There are many health promotions running through the school system throughout Australia at any given time. Health screening programs such as scoliosis detection for girls aged between 10 and 12 years of age are run through schools (Scoliosis Australia, 2024), as well as immunisation programs for teenagers (e.g. HPV – “Gardasil 9” in year 7, and “Meningococcal AWCY” - Nimenrix in Year 10) (NSW Health, 2024a).
3. **GP Incentive to Bulk-Bill children under 16 years:** The Albanese government (Prime Minister at the time of writing) announced that the 2023-2024 budget would include \$3.5 billion AUD (Australian Medical Association, 2023) to financially incentivise GPs to bulk bill their services for more equitable accessibility (Australian Government Department of Health and Aged Care, 2023d) for the 4.8 million children that live in Australia (Australian Institute of Health and Welfare, 2023d).

### **State-funded programs**

1. **Maternal and Child Health Services:** These services are specifically for the antenatal period to early childhood. The services provided include home visits and regular check-ups as outlined in the New South Wales Government “Blue Book”, which outlines the schedule for all the required check-ups and immunisations for every child born in New South Wales. This is a vital aspect of child healthcare in New South Wales, with the Blue Book serving as a way to unite all the health service providers to ensure continuity of care for the child. Every state and Territory has a similar service (NSW Health, 2023c).
2. **The first 2000 days of life:** This program specifically focuses on the whole child’s physical, mental, social and emotional health and development over the first 2000 days of their life (conception to 5 years) to ensure that the child has the best start to their life. The evidence shows that the first 2000 days of a child’s life can have life-long impacts. It is a predictor of a child’s education and learning but also adolescent pregnancy and involvement in the criminal justice system during adolescence. It is also linked to drug and alcohol misuse and violence. It is also related to obesity, elevated blood pressure and depression in 20-40-year-olds, and diabetes and coronary heart disease in 40-60-year-olds. It

can also be a predictor for premature ageing and memory loss in older groups (NSW Health, 2021).

3. Virtual Residential Parenting Service: This is a free online service for NSW families with children 0-3 years who need support with establishing sleeping and settling routines, meeting feeding needs for their children, child development and behaviour and the parent's mental health and wellbeing. It runs for 5 days and 4 nights, much like the traditional residential programs offered by Karitane (Karitane, 2024) and Tresillian (Tresillian, 2023); however, this allows parents who aren't able to leave their homes to have the benefit of the support that they would not receive otherwise (NSW Health, 2024b).

## 1.7 Health of Children in Australia

### 1.7.1 Health status

#### 1.7.1.1 *Life expectancy*

As of June 2023, 4.8 million children (0-14 years) live in Australia. Of those, almost 1.5 million live in New South Wales (Australian Bureau of Statistics, 2023d). The life expectancy for an Australian male born between 2020 and 2022 was 81.2 years, and 85.3 years for a female. In NSW, the life expectancy for a male was 81.3 years and 85.3 years for a female. The region for the highest life expectancy in Australia for males was Sydney–Baulkham Hills and Hawkesbury at 85.7 years. For females, it was highest in Sydney–North Sydney and Hornsby (88.2 years)(Australian Bureau of Statistics, 2023c). Australia has the third highest life expectancy in the world, behind Monaco and Japan, with Australian males ranking second and females sixth (United Nations, 2022) overall.

#### 1.7.1.2 *Burden of disease*

The 2022 report by the Australian Institute of Health and Welfare (AIHW) showed that the burden of disease for children in Australia can be split distinctly between children under 5 and those aged 5-14 (Australian Institute of Health and Welfare, 2022a). For those under 5, the leading causes of total burden of disease were mainly infant conditions, with pre-term birth and low birth weight conditions being the leading cause, followed by birth trauma and asphyxia. Cardiovascular defects were third, followed by Sudden Infant Death Syndrome (SIDS) and asthma (Australian Institute of

Health and Welfare, 2022a). For children aged 5-14, asthma was the leading cause of the burden of disease, followed by four mental health/neurodevelopmental conditions- anxiety disorders, Autism Spectrum Disorders, Conduct Disorder and Depressive disorders (Australian Institute of Health and Welfare, 2022a). These were similar between males and females except for ASD for males and acne for females (Australian Institute of Health and Welfare, 2022a). In 2021-22, children aged 0-11 made up 5.2% (145,000) of all people receiving Medicare-subsidised mental health-specific services (Australian Institute of Health and Welfare, 2023b). The impact of COVID-19 on children can't be underestimated. Kids Help Line reported a doubling of their duty-of-care reporting (i.e. involving police, ambulance, and child safety) to protect children from December 2020 to 31 May 2021, to the same period a year earlier (Yourtown, 2021).

#### *1.7.1.3 Disability and chronic illness*

Disability amongst Australian children is approximately 1 in 13 children (7.5%, or approximately 356,000) of children aged 0-14 (Australian Institute of Health and Welfare, 2023c). It is estimated that 241,000 children aged 5-14 have a schooling restriction as a result of their disability. School restriction is defined by a child's need for aids, equipment or help to participate in their education as a result of difficulty because of their disability (Australian Institute of Health and Welfare, 2023c). In 2022, chronic illness experienced by children 0-14 year-olds was estimated to be 44% (Australian Bureau of Statistics, 2023e). The most common chronic illness for children 0-14 years old were centred around allergy, with hay fever and allergic rhinitis (11%) being most common, followed by asthma (8.7%), which can be triggered or exacerbated by allergy. Allergies were next (including food, drug and undefined) at 7.8%. Mental health conditions followed then by anxiety-related disorders accounting for 7.12% and problems with psychological development (6.8%) (Australian Bureau of Statistics, 2023e).

## 1.7.2 Health risk factors

### 1.7.2.1 Nutrition

The ABS 2022 National Health Survey (NHS) has reported on children's fruit and vegetable intake for children aged 2-14 years of age. Almost 2 in 3 (63.9%) children aged 2-14 years met the NHMRC dietary guidelines (National Health and Medical Research Council, 2013) recommended serving of fruit; however, only 1 in 20 children met the recommended intake for vegetables (4.6%) (Australian Bureau of Statistics, 2011b).

### 1.7.2.2 Physical activity

The most recent data available for children's physical activity and sedentary behaviour is from the ABS 2011-2012 National Nutrition and Physical Activity Survey (NNAPS) (Australian Bureau of Statistics, 2011a). In 2011-2012, 72% of children aged 2-4 years old (pre-school) met the recommended 180 minutes of physical activity per day, with the average being 6 hours of physical activity a day. However, in contrast to this, only 26% met the screen-based activity guideline of no more than 60 minutes a day, with the average spending 83 minutes on sedentary activities, such as watching TV or playing video games. The ratio was inverse, with children aged 5-17 years (school age) spending 91 minutes per day on average on physical activity while 136 minutes on screen-based activities. This trend has been shown to continue, with physical activity decreasing and screen-based activity increasing with age (Australian Bureau of Statistics, 2011a). (NB. Data to update the NNAPS was collected in 2023 but was not available at the time of writing.)

### 1.7.2.3 Overweight and obesity

The majority (67%) of Australian children in 2017 were within the normal weight parameters for their age and height, while 1 in 4 children were considered overweight or obese. The criteria for obesity were met by 7.7% (1 in 13) of children aged 5-14 years. This was similar for boys and girls across all age groups and was stable between 2007 and 2017 (Australian Bureau of Statistics, 2023f).



## 1.8 Families in Australia

There were almost 2.8 million families in Australia in June 2023 (Australian Bureau of Statistics, 2023b) with dependent children under the age of 15. Single-parent families account for 10% of families in Australia with dependent children (Qu et al., 2023).

In 2022, 300,684 births were registered in Australia (Australian Bureau of Statistics, 2023a), representing a decrease of 5.0% (15,021) from 2021 (Australian Institute of Health and Welfare, 2023e). The decrease in birth rates in 2022 was also seen across all states and territories in Australia, with NSW having a decrease of 3.6% from 2021. However, this trend was reversed with Aboriginal and Torres Strait Islander people, with an increase of 878 Aboriginal and Torres Strait Islander babies born in 2021, representing 0.29% of all registered births in Australia in 2022 (Australian Bureau of Statistics, 2023a).

The median age of parents for newborns in 2022 was 31.9 years for mothers and 33.7 years for fathers (Australian Bureau of Statistics, 2023a). Women with higher education qualifications tend to have children later than those who finished formal education at high school, but this is becoming less apparent. Families with 2 children are now the most common, with larger families (3+ children) becoming less common, while the number of families with one child has been increasing (Qu, 2020).

In 2022, 71% of couples (both parents) families with children under 15 were employed, compared to 40% in 1979 (Baxter, 2023). The proportion of both parents working full time has also increased, with 31% of parents in couple families both working full time, compared to 22% in 2009 (Baxter, 2023). For couple families with a child under one, 61% had a stay-at-home mother, 2.5% had a stay-at-home father, 13% had both parents at home, and 24% had both parents at work (Baxter, 2023). There has also been a significant increase in the use of maternity leave entitlements, with 31% of mothers retaining employment but working zero hours in the first year of their child's life, compared to 5% in 1991, allowing mothers to stay in the workforce when having children rather than leaving and recommencing once the children are older (Baxter, 2023).

## 1.9 Parent Health Information Seeking

In retrospect, before the internet and social media, parents were restricted to what we now refer to as 'offline' health information resources when health information seeking. These can include "local experts" who are informally sharing their professional or personal lived experiences of the condition of concern and mass media, such as newspapers, billboards, television and radio (Cotten & Gupta, 2004). While many of these resources are still available today, their utility and access have shifted with the arrival of the Internet and social media.

Much of the current literature discusses the use of 'digital media', which are online resources facilitated by the Internet, including websites, search engines (in particular, Google search (Kubb & Foran, 2022)) and apps for phones (Baumann et al., 2020). Parental seeking trends are reported to be much the same across the developed world, with studies from Austria (Kubb & Foran, 2020), Germany (Lander et al., 2023), Switzerland (Baumann et al., 2020; Jaks et al., 2019), and the UK (Rathbone & Prescott, 2019) showing many similarities, including search engines as the most used form of digital media (Baumann et al., 2020; Jaks et al., 2019; Lander et al., 2023).

In Australia, parents' health information-seeking has followed the same trend as seen internationally (Khoo et al., 2008; Yudianto et al., 2023). In 2008, when social media was in its infancy, parents' most used resource was GPs, followed by pharmacists and the Internet (Khoo et al., 2008). In 2016, the Australian Child Health Poll (Rhodes, 2016) reported that parents (of children 0-18) still use GPs the most, followed by friends and family, and pharmacists when seeking health information for their children. Digital media (websites, blogs, online forums) was the 4<sup>th</sup> most used resource, with 61% of parents polled reporting that they had used health information for their child they had found on digital media in the last 6 months (Rhodes, 2016). For parents of children 5 years and under, 94% of parents used GPs, 88% used friends and family, 75% used pharmacists, and 73% used digital media (websites, blogs, online forums). Other resources used by parents of children 5 years and under included print media (books, magazines, newspapers) (64%), Well child nurses (54%), Hospitals including emergency (49%), Paediatricians (47%), schoolteacher, childhood educator (46%), and telephone advice helpline (42%).

Trust is a common theme when parents are looking for health information. What is of particular interest are the contradictions between which sources of information parents report to trust and which they use. For example, in the 2016 Australian Child Health Poll, 6% of parents reported that they trust digital media (websites, blogs and online forums) 'a lot', but 73% of parents with children 0-5 years reported using digital media in their health information seeking. For the entire cohort (children aged 0-17) 61% of parents reported using digital media health information in the previous six months. This extends to parents' trust when disclosing and discussing the information they found online with their GPs, with only 22% of parents stating that they would always discuss the information they found online with their GP, while 58% said they sometimes discussed information found online. The remaining 20% of parents reported they would never discuss information they found online with their GP (Rhodes, 2016).

For many parents, the GP's role has shifted with respect to health information-seeking, with more parents using GPs for verification of information found online (and in particular social media) rather than being a primary source of health information (Frey et al., 2024; Yudianto et al., 2023). Indeed, 92% of parents stated that they would like their GP (or other health professional) to help them with guidance for searching for health information online, assessing its trustworthiness and understanding the information found (Yudianto et al., 2023), an increase from 69% of parents in 2018 study (Yardi et al., 2018).

### 1.10 The rise and impact of social media

Having evolved from the Internet, the definition of social media has long evaded consensus. Reasons for this include the fast pace at which platforms evolve, develop and provide functions and services (boyd & Ellison, 2007) and how quickly those functions and services are integrated into everyday life (boyd & Ellison, 2007; Ellison & boyd, 2013; Van Dijck, 2013). For the purposes of this thesis, we have chosen to use Kaplan & Haenlein's (2010) definition of social media:

“a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0 and that allow the creation and exchange of user-generated content” (Kaplan & Haenlein, 2010, p. 61).

This definition captures the functions that have positioned social media as a leading information resource. The platforms act as enduring repositories for information generated by users and allow users to retrieve and exchange information between the platform and the Internet (Web 1.0) seamlessly and interchangeably. The result of this one key difference (Hamm et al., 2013; Van Dijck, 2013) is that parents can seek, and access user-generated information based on both opinions (Dylko & McCluskey, 2012) and evidence when making health decisions for their children. Parents are, therefore, left to not only interpret the information that they find but also to decide if it is relevant, trustworthy and ultimately safe to use.

Within Kaplan and Haenlein’s framework, there are six broad categories of social media, including- blogs (e.g. WordPress), collaborative projects (e.g. Wikipedia), social networking sites (e.g. Facebook, Instagram), content communities (e.g. YouTube), virtual social worlds (e.g. Second Life), and virtual game worlds (e.g. World of Warcraft) (Kaplan & Haenlein, 2010). Social media has evolved swiftly and somewhat exponentially to what we know it to be now since its debut in 1997 with Six Degrees (Table 1.1).

Where traditionally parents might have approached a healthcare professional for evidence-based information upon which to make health decisions, many are now accessing information independently on social media. Some of the trusted information that circulates on social media may lack an evidence base but still has gained currency due to a lack of relevant (also known as ‘information poverty’) (Drushel, 2013; Wang & Lund, 2020) and accessible, well-translated, evidence-based information for those who need it most.

#### *1.10.1.1 Social media use in Australia*

Social media use in Australia is widespread, with 81.0% (approximately 21.3m) of the whole population being active on social media in January 2023 (We are Social &

Meltwater, 2023). In 2022, social media use for the population aged over 13 was 99.4% (We are Social & Hootsuite, 2022). The vast majority of users use their mobile phones to access social media; for example, 97.6% of Facebook users access the platform by their phone (We are Social & Hootsuite, 2022). The average number of social platforms used by social media users was 6.1 (We are Social & Hootsuite, 2022).

Social media was the second most popular activity for Australians in 2022, spending 1 hour and 57 minutes a day on social media (an increase of 10.4 % from the previous year), second only to watching television. In 2023, this increased again by 6% year on year, with a total average of 2 hours and 4 minutes of time spent on social media every day in 2023 (We are Social & Meltwater, 2023).

The top reasons given by internet users 16-64 years of age for using social media in 2023 (We are Social & Meltwater, 2023) included:

1. Keeping in touch with family and friends (54.3%)
2. Filling in spare time (38.2%)
3. Reading news stories (24.8%)
4. Finding content (24.7%)
5. Looking for things to do or buy (23.2%)
6. Seeing what's being talked about (22.9%)
7. Finding like-minded people (20.4%)

Engagement on social media in 2021 saw Facebook (17.6 hours/ month) eclipsed by TikTok (23.4 hours/month) by time spent per month for the first time (We are Social & Hootsuite, 2022). Time spent on TikTok increased by 40% from the start of 2021. In 2023, TikTok's dominance became even more pronounced, with the average time spent on TikTok being 29 hours 36 minutes (an increase of 26.5% year on year), in comparison to Facebook's 17 hours and 48 minutes which was an increase of 1.1% year on year. Other platforms included in this analysis were YouTube (17h06m), Instagram (8h36m) and WhatsApp (5h36m) (We are Social & Meltwater, 2023).

Despite the amount of time spent on Facebook by users falling, Facebook (73.6%) still remains the most used social media platform by number of active users in 2023. This is

followed by Facebook Messenger (62.9%), Instagram (55.5%), TikTok (41.5%), iMessage (35.1%), WhatsApp (34.7%), Snapchat (33.0%), Twitter/X (30.7%), Pinterest (28.6%), LinkedIn (26.2%), Reddit (23.4%), Skype (16.1%), Discord (13.8%), Telegram (10.6%), Tumblr (8.8%).

Facebook remains the most favoured social media platform for users 16-64 years old (25.6%) despite falling from 27.2% in 2022. This has been the case for all platforms, including Instagram (14.3%), Facebook Messenger (8.9%), WhatsApp (5.3%), Snapchat (4.2%) and Reddit (2.7%). The only exception was TikTok which has seen more than 100% increase from 6% in 2022 to 12.5% in 2023) (We are Social & Hootsuite, 2022; We are Social & Meltwater, 2023).

Table 1.1 Evolution of selected social media platform timeline\*

Year	Selected Social Media Platform Timeline
1969	APRANET (first network using technology that evolved into the modern internet) <sup>c</sup>
1973	Talkomatic (real-time online text communication) <sup>c</sup>
1978	Bulletin Board System <sup>b</sup>
1980	Usenet <sup>b</sup> , CompuServe develops CB simulator (first online chat service) <sup>c</sup>
1984	Short Message Service (SMS) concept developed <sup>b</sup>
1985	WELL (whole Earth 'Lectronic Link) <sup>c</sup> , AppleLink (later became America Online) <sup>c</sup>
1986	LISTSERV automated management of email lists <sup>c</sup>
1988	Internet Relay Chat <sup>b</sup>
1989	America Online (AOL) launches Instant Messenger <sup>c</sup>
1992	First photo published online <sup>c</sup>
1994	Geocities <sup>c</sup>
1995	First wiki site <sup>b</sup> , ebay <sup>b</sup> , Amazon <sup>c</sup> , Craigslist <sup>c</sup> , Classmates <sup>c</sup>
1996	First smartphone (Nokia 9000 Communicator) <sup>b</sup>
1997	"weblog" <sup>b</sup> , SixDegrees.com <sup>a</sup>
1998	Yahoo groups <sup>b</sup>
1999	Liver Journal <sup>a</sup> , Blogger.com <sup>b</sup> , AsianAvenue <sup>a</sup> , BlackPlanet <sup>a</sup> , RSS feeds <sup>c</sup> , Pitas <sup>c</sup> , DiaryLand <sup>c</sup> , Blogger <sup>c</sup> , Napster <sup>c</sup> , Cyworld <sup>a</sup>
2000	LunarStorm <sup>a</sup>
2001	Wikipedia <sup>b</sup> , Google groups <sup>b</sup> , Tripadvisor <sup>b</sup> , Cyworld <sup>a</sup> , Ryze <sup>a</sup>
2002	Friendster <sup>a</sup> , Last.fm <sup>b</sup> , Fotolog <sup>a</sup>
2003	MySpace <sup>a</sup> , WordPress <sup>b</sup> , Del.ici.ous <sup>b</sup> , LinkedIn <sup>a</sup> , Second Life <sup>b</sup> , Skype <sup>b</sup> , 4 Chan <sup>b</sup> , Tribe.net <sup>a</sup> , Couchsurfing <sup>a</sup> , hi5 <sup>a</sup> , iTunes Music Store <sup>c</sup> , Baidu Tieba <sup>d</sup>
2004	Facebook (Harvard only) <sup>a</sup> , Flickr <sup>a</sup> , World of Warcraft <sup>c</sup> , Orkut <sup>a</sup> , Dogster <sup>a</sup> , Piczo <sup>a</sup> , Mixi <sup>a</sup> , Multiply <sup>a</sup> , aSmallWorld <sup>a</sup> , Dodgeball <sup>a</sup> , Care <sup>b</sup> , Catstera <sup>a</sup> , Hyves <sup>a</sup> , Digg <sup>b</sup> , term "podcasting" is coined <sup>b</sup> , first "Web 2.0" conference <sup>b</sup>
2005	YouTube <sup>a</sup> , Yahoo!360 <sup>a</sup> , Cyworld <sup>a</sup> , Bebo <sup>a</sup> , Ning <sup>a</sup> , Xanga <sup>a</sup> , podcasts <sup>c</sup> , Reddit <sup>c</sup>
2006	Facebook (corporate networks then everyone) <sup>a</sup> , Twitter <sup>a</sup> , QQ <sup>a</sup> , Windows Live Spaces <sup>a</sup> , My Church <sup>a</sup>
2007	Justin TV <sup>b</sup> , Tumblr <sup>b</sup> , Gowalla <sup>b</sup> , Zynga- Texas Hold 'Em Poker <sup>c</sup> , iPhone <sup>c</sup>
2008	9GAG <sup>b</sup> , Groupon <sup>c</sup> , Apple App Store <sup>c</sup>
2009	Foursquare <sup>b</sup> , Google Wave <sup>b</sup> , Chatroulette <sup>b</sup> , Weibo <sup>b</sup> , Klout <sup>b</sup> , Zynga- FarmVille <sup>c</sup> , WhatsApp <sup>c</sup>
2010	Instagram <sup>b</sup> , Pinterest <sup>c</sup> , Kik <sup>c</sup> , Diaspora <sup>*b</sup> , WeChat <sup>b</sup> , Viber <sup>d</sup>
2011	Google+ <sup>b</sup> , Snapchat <sup>b</sup> , twitch <sup>e</sup>
2012	Facebook Messenger <sup>c</sup> , Tinder <sup>d</sup>
2013	Vine <sup>c</sup> , Yahoo acquires Tumblr <sup>c</sup> , Patreon <sup>e</sup> , Telegram <sup>e</sup>
2014	Facebook acquires WhatsApp <sup>c</sup>
2015	Meerkat <sup>c</sup> , Periscope <sup>c</sup> , Facebook Live <sup>c</sup> , Discord <sup>d</sup>
2016	Instagram Stories <sup>c</sup> , Mastodon <sup>e</sup>
2017	TikTok <sup>d</sup> , Substack <sup>e</sup> , Counter Social <sup>e</sup>
2018	Yahoo! Messenger shuts down <sup>d</sup> , Parler <sup>e</sup> , Musical.ly shuts down – migrates users to TikTok <sup>e</sup>
2019	Google+ shuts down <sup>d</sup> , Hive Social <sup>e</sup> , BeReal <sup>f</sup>
2020	Clubhouse-ios <sup>f</sup> , Instagram Reels <sup>f</sup> ,
2021	Clubhouse-android <sup>f</sup> , Spotify Greenroom <sup>f</sup> , Polywork <sup>f</sup> , Gettr <sup>f</sup> , TruthSocial <sup>f</sup>
2022	Spotify Live <sup>f</sup> , Locket <sup>f</sup> , YikYak (relaunch) <sup>f</sup>
2023	Threads <sup>f</sup> , Lemon8 <sup>f</sup> , Nostr <sup>f</sup> ,

<sup>a</sup>(boyd&Ellison, 2007) <sup>b</sup>(Page, Barton, Unger & Zappavigna 2014) <sup>c</sup>(Burns, 2017) <sup>d</sup>(Wikipedia, 2019) <sup>e</sup>(Wikipedia 2023) <sup>f</sup>(Samur & Christion 2023)

\*Updated from Brunner 2020 (thesis), non-exhaustive

## 1.11 Research Aim, Objectives, and Questions

### 1.11.1 Research aim

This research aims to enhance our understanding of the determinants, motivations and experiences of Australian parents using social media for health information for their children.

### 1.11.2 Research objectives

1. To describe the prevalence of Australian parents who use social media for health information for their children.
2. To determine the characteristics, determinants and motivations of Australian parents that use social media for health information for their children.
3. To explore how parents use social media to find health information for their children and which platforms they access.
4. To discover if a parent's health literacy impacts their use of social media for health information for their children.
5. To find out if a parent's critical thinking ability impacts their use of social media for health information for their children.

### 1.11.3 Research questions

1. How many Australian parents use social media for health information for their children?
2. What are the characteristics, determinants and motivations of Australian parents that use social media for health information for their children?
3. How do Australian parents use social media to find health information for their children and which platforms do they access?
4. Does a parent's health literacy impact their use of social media for health information for their children?
5. Does a parent's critical thinking ability impact their use of social media for health information for their children?



## 1.12 Significance and Scope of this Thesis

Parents are responsible for their child's health until such an age where the child themselves are able to understand health information, understand and anticipate consequences for decisions made and weigh up the risks and benefits of any decision made. A child's health also does not only impact the child in the moment, but it can have ongoing impacts for the child throughout their life, as well as impacts on a child's broader family and the community they are part of. Finding, accessing, understanding, and evaluating health information is crucial to a parent's ability to care for a sick child. Social media has made health information easier to access, but it has also complicated the other aspects of health information seeking.

This research is significant as it aims to describe and clarify this phenomenon, which has had little enquiry previously. The impact of using social media for health information has been far-reaching, impacting not only individuals and their families but also clinical services, public health, and health systems worldwide.

The aim of this thesis is to explore Australian parents' use of social media for health information, including the prevalence of their use, the motivations for their use, and their experiences that have resulted from using social media for health information.

## 1.13 Structure of the Thesis

This thesis is comprised of seven chapters, including four peer-reviewed papers – two published and two under review.

**Chapter 1** introduces how the researcher became interested in the research area in this thesis. Key background concepts are also introduced– the Australian health system, the health status of children in Australia, parenting in Australia as well as social media.

**Chapter 2** presents the methods and methodology underpinning this research. This includes the research design, how data were collected, and the data analyses used.

**Chapter 3** is a scoping review (peer-reviewed and published) that explores the extant literature to determine what is already known about parents' motivations, sentiments and experiences of using of social media for health information.

**Chapter 4** is a representative, quantitative study (peer-reviewed and published) examining the extent to which Australian parents (n=1000) use social media for health information. This is the first of two quantitative publications all using the same dataset in this research.

**Chapter 5** is the qualitative study (under review), that dives deep into Australian parents' (n=19) experience using social media for health information, as told by the parents in their own words.

**Chapter 6** is the second quantitative study (under review), where parental health literacy skills and self-perceived critical thinking skills were analysed to determine if either impacted a parent's propensity to use social media for health information for their child. Increased parental health literacy was found to be a predictor of less use of social media for health information.

**Chapter 7** presents a discussion of all the studies to respond to the research objectives. Hypotheses for future research and the research's impact are also discussed, as well as the study's limitations and strengths. The conclusion finishes the thesis by answering the research question – Why do Australian parents use social media for health information for their children?

## 1.14 Chapter Conclusion

This chapter has explained how I came to this research through a combination of professional and personal experiences. This is then followed by background information to position the research, including overviews of the Australian health system and programs for children, the health status of children in Australia, as well as some descriptive statistics about families in Australia. The evolution of social media is briefly discussed. Concluding the introduction, the research aims, objectives and

questions are detailed, as too are the significance and scope of the doctoral thesis's research, finishing with an overview of the structure of this thesis.

The following chapter presents the published scoping review that was undertaken to meet the first research objective of exploring the extant literature to understand what is already known about this phenomenon.

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## Chapter 2: Scoping Review

### 2.1 Introduction

This chapter presents the scoping review published as the inaugural scoping review for *Academic Pediatrics* in 2022 (see the formal citation below). It was undertaken as the initial phase of this research to address the initial questions about what was already known in the literature about parents' use of social media for health information for their children. It also looked at the parents' motivations in engaging with social media to seek health information, how they sought to understand and evaluate the results of their searches and their impact on parental health information-seeking strategies. The article answered the question about what is already known in the literature about this phenomenon.

This scoping review included 42 peer-reviewed studies published between 2011 and 2020 (with open date filters), including quantitative (n=15), qualitative (n=22), mixed methods (n=4) and an integrative review (n=1).

It was guided by the PRISMA extension for scoping reviews to allow for a systematic but flexible approach to this review (Tricco et al., 2018; PRISMA, 2021). New findings included parents' use of social media for health information for specific concerns both before and after a diagnosis for their child, alongside their strong desire for health information based on lived experience, encompassing community and social support from other parents.

### 2.2 Publication Details

This paper was accepted for publication as the inaugural scoping review for *Academic Pediatrics* (2023 Impact Factor 3.1) in December 2021 and published in June 2022. It is currently the 5<sup>th</sup> most cited paper for the journal in the last 3 years, with 65 citations (Google Scholar) and one mention in mainstream news at the time of writing (April 2024). The editors of *Academic Pediatrics* have invited the authors to do an update with a COVID-19 focus.

Frey, E., Bonfiglioli, C., Brunner, M., Frawley, J. (2022) Parents' use of social media as a health information source for their children: A Scoping Review. *Academic Pediatrics*. DOI: doi.org/10.1016/j.acap.2021.12.006

Supplementary material included with article published online

1. [Search Strategy](#)
2. [Data Extraction Tool](#)

## 2.3 Parents Use of Social Media as a Health Information Source for Their Children: A Scoping Review

### SCOPING REVIEW

# Parents' Use of Social Media as a Health Information Source for Their Children: A Scoping Review



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### ABSTRACT

**BACKGROUND:** Parents are increasingly using social media to inform health decisions for their children.

**OBJECTIVE:** This scoping review examines 1) How do parents use social media to find health information for their children? 2) What motivates parents to engage with social media to seek health information for their children? 3) How do parents seek to understand and evaluate the health information they find on social media, and how does social media impact parental health information-seeking?

**METHODS:** Scopus, CINAHL, Medline, PubMed, and Embase databases were searched, with open date parameters. Peer-reviewed studies that examined parents' and responsible caregivers' use of social media as a source of health information for their children (aged <18 years) were included.

**RESULTS:** The 42 included studies spanned 2011 to 2020. More than half (n = 24, 57%) were published in 2019 and 2020. Parents use social media for information about specific

health concerns both before and after a medical diagnosis for their child. Parents are motivated to engage with social media as they seek out extensive information based on lived experience from other parents, as well as social support and community.

**CONCLUSION:** This scoping review reveals parents' motivation to use social media for health information, and how that can interact with, and impose on, clinical practice. It is important for those who provide pediatric health care to both understand and accommodate this permanent shift facilitated by social media, when working with parents who are seeking health information when making health decisions for their children.

**KEYWORDS:** adolescent; child; health behavior; infant; information-seeking behavior; parents; preschool; social media

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### How to Use This Scoping Review

- To aid in clinical care as a basis for asking parents if and how they access health information through social media.
- To develop research programs investigating how health information is sourced on social media.
- To inform policy relating to how parents source and use health information found on social media.

### WHAT THIS SCOPING REVIEW ADDS

A concise overview of how parents use social media as part of their health information seeking process, what motivates parents to use social media, and how this use of social media can impact and impose on the provision of health care and clinical practice to children as it has been delivered up until now.

PARENTS ARE INCREASINGLY USING social media to seek health information for their children.<sup>1</sup> Social media allows parents to form emotionally and socially supportive communities despite geographical barriers. It also facilitates the exchange of information between parents who might not have connected otherwise. However, social media may challenge parents' health literacy skills<sup>2</sup> in new ways due to the lack of expert input,<sup>3</sup> and fact-checking regulatory gatekeeping, that underpin the factual authority of traditional news media.<sup>4,5</sup>

Engagement is central to social media,<sup>6,7</sup> allowing multiple conversations to occur irrespective of geography and time. Information is exchanged between parents much like an ordinary conversation, but exchanges are digitized and available to those with access. This fundamental difference<sup>4,8</sup> means parents may access evidence-based,

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user-generated information, but, unwittingly, also opinion which is not based on fact,<sup>9</sup> and may even be contradictory. This also may create confusion,<sup>10</sup> delay access to health care,<sup>11</sup> or increase the use of treatments without medical oversight,<sup>8</sup> possibly harming children's health.

Researchers have investigated the quality of information on social media and the Internet; however, insight into parents' use of social media to seek health information for their children is limited.<sup>8,19</sup> Accordingly, we conducted a scoping review of relevant peer-reviewed research to answer the following research questions: 1) How do parents use social media to find health information for their children? 2) What motivates parents to engage with social media to seek health information for their children? 3) How do parents seek to understand and evaluate the health information they find on social media, and how does social media impact parental health information seeking?

### METHODS

The PRISMA-ScR methodology was chosen due to the heterogeneity of study designs, platforms used, the variety of health issues parents sought information for, and this being a new area of study.<sup>12,13</sup> The PRISMA-ScR allowed us to map the existing scholarly literature<sup>14</sup> and identify future research directions,<sup>13,15</sup> while also allowing for flexibility when deciding which literature sources were to be included and excluded by design<sup>14</sup> and preserving research integrity and rigor. A review protocol was developed (but not registered) *a priori* in compliance with the protocol outlined in the Joanna Briggs Institute Manual of Evidence Synthesis,<sup>16</sup> using the SUMARI protocol template<sup>17</sup> provided. The reporting for the scoping review was done in compliance with the PRISMA-ScR extension,<sup>12</sup> using the PRISMA-ScR checklist.

The inclusion and exclusion criteria were determined *a priori*. Peer-reviewed scholarly research (published in English) that examined parents with a child aged between 0 and 18 years of age that specified social media as a source of health information were included. The term 'parent' is used here as an all-inclusive term, encompassing biological and non-biological caregivers responsible for the health decisions of a dependent child younger than 18 years. Studies were excluded if they included parents of children over 18 years of age, were concerning pregnancy/prenatal care, or included children under the age of 18 years seeking their own health information. Studies on mHealth were excluded along with studies that did not clearly differentiate the use of the Internet from that of social media.

Embase, Scopus, CINAHL, and Medline were searched on August 30, 2020 with identical but translated search strategies. A targeted search of *Journal of Medical Internet Research* through PubMed (journal specified) was also conducted on September 22, 2020. All peer-reviewed empirical research was included,

with all other search results being excluded to limit bias which is known to be inherent in editorials based on opinion, and lack of peer review for conference abstracts. Gray literature (literature that is produced by governments, academics, businesses and industry, but is not formally controlled or published by publishing houses<sup>18</sup>) was excluded due to the inability to determine quality,<sup>19</sup> and impartiality.<sup>24</sup>

The search terms used were developed with the assistance of an information services librarian. Search terms used across the databases were identical but translated to work for the requirements of each database (see Appendix 1). Date filters were left open (ie no date filters were used to limit results) to include studies across the entire social media lifespan and enable us to view changes and trends over time. The search strategy was executed by the first author with assistance from the consulting information services librarian.

The results from all searches were exported to Covidence<sup>20</sup> where duplicates were removed within the program, manually double-checked and deleted manually where required. Two reviewers (E.F. and M.B.) screened all papers by title, abstract and full paper according to the eligibility criteria that was inputted into Covidence to assist with consistency between reviewers and within screening for each reviewer. Inconsistencies were discussed between the two screening reviewers. Two papers that could not be resolved between the two screening reviewers were referred to the entire authorship team for discussion as to eligibility, resulting in one paper being included and one paper being excluded. Studies that appeared in records more than once were collapsed into a single unit (first study published) for the purposes of analysis. The screening process was guided by the scoping review protocol.<sup>16</sup>

The data were extracted based on participant, concept, context in an iteratively adjusted data extraction tool (see Appendix 2) as set out in the scoping review protocol. Participant data was primarily focused on demographics. Concept data extraction focussed on data needed to directly answer the research questions – such as parent's behavior, motivation, and sentiment related to social media use for health information. Self-reported outcomes (what parents did with or as a result of the health information they found on social media) were also extracted to provide additional insights. Context data extraction focussed on study methodology and setting, including the country in which the study was conducted, the data collection methods and study designs used, the year of data collection, and the social media platforms investigated. Finally, the study data extracted was related to the meta data needed to inform the review. Once data extraction was completed, data synthesis was initiated on Microsoft Excel utilising data filters to dynamically group studies together that had similarities, depending on the data point being explored at the time. Data were then mapped to allow for comprehensive analysis and cohesive results (Tables 1 and 2).

**Table 1.** Overview of the Characteristics of the Included Studies

Author	Year	Country	Study Design	Total Data Set (n=)	Health Concern	SM Platforms Used	Funding Statement
Adekunle <sup>21</sup>	2020	Nigeria	Survey	50 participants	Orofacial cleft	Facebook Instagram Twitter	None declared
Bamashmous et al <sup>22</sup>	2020	UK	Survey	70 participants	Dental trauma	YouTube Wikipedia Facebook Dental forums	Absent
Bradshaw et al <sup>37</sup>	2020	US	Content analysis	258 participants	Vaccines	Facebook	Absent
Bryan et al <sup>1</sup>	2020	US	Survey	551 participants	General information	Facebook Wikis blogs	Bright futures Young Investigators Award from Academic Pediatric Association and Maternal Health Bureau
Clapton-Caputo et al <sup>36</sup>	2020	Australia	Interview	76 participants	Breastfeeding	Facebook	None declared
Jenkins et al <sup>39</sup>	2020	US	Content analysis	64 participants	Vaccines	Blogs (comments)	Absent
Kim et al <sup>23</sup>	2020	US	Survey	4174 participants	Measles	Facebook Twitter Instagram Pinterest	Supported by the Department of Communication at George Mason University
Lebron et al <sup>40</sup>	2020	US	Content analysis	258 posts/ 1445 comments	Breastfeeding	Babycentre.com forum	Absent
Pretorius et al <sup>41</sup>	2020	US	Content analysis	20 posts/ 912 comments/ 512 mothers in one Facebook group	Sudden Infant Death Syndrome	Facebook	- Sigma Theta Tau - National Association of Pediatric Nurse Practitioners
Raspa et al <sup>56</sup>	2020	US	Interview Survey	7 participants 76 participants	Severe Combined Immune Disorder	Not specified	Health Resources and Services Administration (HRSA) of the US Department of Health and Human Services (HSS) (Grant #SC1MC31881).
Thorpe et al <sup>42</sup>	2020	Australia	Interview	14 participants	Vaccines	Facebook YouTube Instagram Pinterest LinkedIn Twitter	None declared
Wang and Lund <sup>43</sup>	2020	US	Content analysis	100 comments	Rare genetic disorders	Facebook	None declared
Castro et al <sup>44</sup>	2019	Canada	Interview	18 participants	Osteogenesis imperfecta	YouTube Facebook	- Tunis Shriners, - Newton Foundation, - Scotiabank,

(Continued)



Table 1. (Continued)

Author	Year	Country	Study Design	Total Data Set (n=)	Health Concern	SM Platforms Used	Funding Statement
Deas et al <sup>45</sup>	2019	US	Interview Focus group	6 participants 33 participants	Vaccines	Not specified	- Canadian Institutes of Health Research: Institute of Health Services and Policy Research Travel Awards (summer 2018) - McGill University Ingram School of Nursing Summer Bursary Program of 2019 - Intercommunity Health Network Coordinated Care Organization - Corvallis Clinic Foundation - Community Health Centers of Benton and Linn Counties - Anonymous individuals
Gage- Bouchard et al <sup>35</sup>	2019	US	Interview	40 participants	Childhood cancer	Facebook	- Supportive Care Research Grant from St Baldrick's Foundation - National Care Institute (NCI) grant P30CA016056
Garcia et al <sup>57</sup>	2019	UK	Interview Survey	64 participants 21 participants	Feeding	Facebook YouTube	Absent
Gorman et al <sup>46</sup>	2019	Scotland	Focus group	13 participants	Vaccines	Facebook Wikipedia	None declared
Hwang and Shah <sup>24</sup>	2019	US	Survey- secondary analysis	4174 participants	Vaccines	Facebook Twitter	Absent
Koskan et al <sup>47</sup>	2019	US	Interview	26 participants	Vaccines	Facebook	Absent
Kulhas Celik et al <sup>25</sup>	2019	Turkey	Survey	458 participants	Food allergies	Facebook	Absent
Moon et al <sup>48</sup>	2019	US	Interview Focus group	28 participants	General information	Facebook	National Institute for Minority Health and Health Disparities 1R01MD007702
Peterlein et al <sup>26</sup>	2019	Germany	Survey	519 participants	Orthopedics	Wikipedia Facebook YouTube Netdoktor.de Other forums Twitter Myspace	None declared

(Continued)

Table 1. (Continued)

Author	Year	Country	Study Design	Total Data Set (n=)	Health Concern	SM Platforms Used	Funding Statement
Pretorius et al <sup>60</sup>	2019	US	Integrative review	12 papers	General support	Facebook YouTube	Absent
Zhao et al <sup>34</sup>	2019	US	Network analysis	5 Facebook groups	Autism Spectrum Disorder	Facebook	Jiangsu Province Social Science Foundation (#19TQC005)
Baker and Yang <sup>27</sup>	2018	Australia	Survey	117 participants	General support	Facebook	Sigma Theta Tau, Gamma Omega Chapter at Virginia Commonwealth University
Lee <sup>28</sup>	2018	US	Survey	480 participants	General information	Facebook Instagram Forums YouTube Flickr Twitter	Absent
Price et al <sup>10</sup>	2018	Canada	Focus group e-interview	19 participants	General information	Forums Blogs Facebook	Bridge Funding from Canadian Institutes of Health Research (CIHR)
Rehman et al <sup>49</sup>	2018	Canada	Content analysis	1700 tweets	Childhood cancer	Twitter	None declared
Gibson et al <sup>58</sup>	2017	US	Interview Survey	6 participants 629 participants	Autism Spectrum Disorder	Facebook Twitter Pinterest Forums	None declared
Nicholl et al <sup>59</sup>	2017	Ireland	Focus group Survey	8 participants 121 participants	Non-specific childhood disabilities	Facebook Twitter LinkedIn Blog	Saoirse Foundation
Walker et al <sup>29</sup>	2017	US	Survey	165 participants	General information	Babycentre.com forum YouTube Facebook	St David's Center for Health Promotion and Disease Prevention Research in Underserved Population, School of Nursing, The University of Texas at Austin.
Kim et al <sup>50</sup>	2016	US	Content analysis	29 social networking sites/ 131 posts	Premature infants	Blogs Facebook forums	None declared
Lupton <sup>51</sup>	2016	Australia	Focus group	36 participants	General information	Pinterest Instagram Facebook YouTube	Personal research funds received from University of Canberra, Australia.
Orr et al <sup>36</sup>	2016	Israel	Content analysis		Vaccines	Facebook	- I-CORE Program of the Planning and Budgeting

(Continued)

Table 1. (Continued)

Author	Year	Country	Study Design	Total Data Set (n=)	Health Concern	SM Platforms Used	Funding Statement
				7 social media platforms / 2289 Facebook comments			Committee, The Israel Science Foundation (1716/12) - Israel Science Foundation grant (1599/15).
Sharpe et al <sup>30</sup>	2016	Canada	Survey	34 participants	Autism Spectrum Disorder Cerebral Palsy	Facebook Twitter Blogs Forums	- Stem Cell Network, Public Policy Impact grant: Stem cell therapies for neuro- developmental disorders: Science, media and pub- lic opinion (13/5226 (PP68)) - NeuroDevNet, Inc. Absent
Al-Daihani and Al- Ateeq <sup>31</sup>	2015	Kuwait	Survey	240 participants	Non-specific childhood disabilities	Not specified	JWB: NIH grants - R01MD003963 - 3T32DK7477-30 S1
Criss et al <sup>52</sup>	2015	US	Focus group	49 participants	General information	YouTube Facebook babycentre.com forum	SC: - Predoctoral training grant from NIH award # 3R25CA057711 - Initiative to maximize Stu- dent Diversity Aware # GM055353-13 - Maternal and Child Health Bureau Award #T03MC07648
Holtz et al <sup>32</sup>	2015	US	Survey	647 participants	Non-specific childhood disabilities	Facebook	None declared
Mohd Roffeei et al <sup>53</sup>	2015	US	Content analysis	381 Facebook posts + 3256 Facebook comments	Autism Spectrum Disorder	Facebook	University of Malaya High Impact Research Grant (No. UM.C/625/1/HIR/ MOHE /FCSIT/16/H- 22001-00-B00016)
Appleton et al <sup>54</sup>	2014	Australia	Content analysis	2 discussion forums/ 34 threads	Childhood obesity	Forums	None declared
Naftel et al <sup>33</sup>	2013	US	Survey	300 participants	Hydrocephalus	Wikipedia Facebook YouTube Myspace	Absent
Cowie et al <sup>55</sup>	2011	Australia	Content analysis	1614 posts/206 users on 1 discussion forum	Breastfeeding	ABA Forum	Absent

**Table 2.** Context Motivating Parents' Health Information Seeking on Social Media

Author	Year	Health Concern/Question	Function of Information Seeking on Social Media
Adekunle et al <sup>21</sup>	2020	Cleft palate	Post diagnosis information seeking
Bamashmous et al <sup>22</sup>	2020	Dental trauma	Preconsultation self-triage
Bradshaw et al <sup>37</sup>	2020	Vaccination	Self-directed health decision making
Bryan et al <sup>1</sup>	2020	Rare childhood conditions & special needs	Postdiagnosis information
Clapton-Caputo et al <sup>38</sup>	2020	Breastfeeding	Self-directed health care
Lebron et al <sup>10</sup>	2020	Breastfeeding	Self-management- support seeking
Raspa et al <sup>56</sup>	2020	Severe Combined Immune Disorder	Postdiagnosis information seeking
Thorpe et al <sup>42</sup>	2020	Vaccination	Self-directed health decision making
Wang & Lund <sup>43</sup>	2020	Costello Syndrome	Postdiagnosis information and support
Deas et al <sup>45</sup>	2019	Vaccination	Self-directed health decision making
Gage Bouchard et al <sup>35</sup>	2019	Childhood cancer	Post diagnosis caregiving information
Garcia et al <sup>57</sup>	2019	Complementary feeding	Self-directed health care
Gorman et al <sup>46</sup>	2019	Vaccination	Self-directed health decision making
Hwang & Shah <sup>24</sup>	2019	Vaccination	Self-directed health decision making
Kulhas-Celik et al <sup>25</sup>	2019	Food allergy	Pre-consultation self-triage
Moon et al <sup>48</sup>	2019	General information	
Pretorius et al <sup>50</sup>	2019	General information	
Zhao et al <sup>34</sup>	2019	Autism Spectrum Disorder	Postdiagnosis information and support
Baker & Yang <sup>27</sup>	2018	General information	
Lee <sup>28</sup>	2018	General information	
Price et al <sup>10</sup>	2018	General information	
Rehman et al <sup>49</sup>	2018	Childhood cancer	Postdiagnosis support and health promotion
Gibson et al <sup>58</sup>	2017	Autism	Postdiagnosis information and support
Nicholl et al <sup>59</sup>	2017	Rare childhood conditions	Postdiagnosis information and support
Kim et al <sup>50</sup>	2016	Premature child in Neonatal Intensive Care Unit	Postdiagnosis information and support
Lupton <sup>51</sup>	2016	General information	
Al-Daihani & Al-Ateeqi <sup>31</sup>	2015	General childhood disabilities	Postdiagnosis information
Criss et al <sup>52</sup>	2015	General information	
Holtz et al <sup>32</sup>	2015	Vaccination	Self-directed health decision making
Mohd Roffeei et al <sup>53</sup>	2015	Autism Spectrum Disorder	Postdiagnosis information and support
Appleton et al <sup>54</sup>	2014	Childhood obesity	Postdiagnosis information and support
Nafel et al <sup>33</sup>	2013	Hydrocephalus	Postdiagnosis information and support
Cowie et al <sup>55</sup>	2011	Breastfeeding	Self-directed health care

## RESULTS

### STUDY CHARACTERISTICS

A total of 42 papers met the inclusion criteria (Fig. 1). The publication dates spanned from 2011 to 2020 (Fig. 2). Included studies used methodologies such as quantitative (n = 15),<sup>1,21-34</sup> qualitative (n = 22),<sup>10,35-55</sup> and mixed methodology (n = 4)<sup>56-59</sup> or review (n = 1).<sup>60</sup> The majority of studies were conducted in the United States (US) (n = 23),<sup>1,23,24,28,29,32-35,37,39-41,43,45,47,48,50,52,53,56,58,60</sup> followed by Australia (n = 6),<sup>27,38,42,51,54,55</sup> Canada (n = 4),<sup>10,30,44,49</sup> and UK (n = 2).<sup>22,57</sup> Germany,<sup>26</sup> Ireland,<sup>59</sup> Israel,<sup>36</sup> Kuwait,<sup>31</sup> Nigeria,<sup>21</sup> Turkey,<sup>25</sup> and Scotland<sup>46</sup> each accounted for one study. Seven studies included only mothers,<sup>10,32,40,46-48,51</sup> one study included only fathers<sup>50</sup> and 19 included both parents and/or caregivers.<sup>1,21,24,26,30,31,33,35,36,42,44,45,49,53,54,56-59</sup> Table 1 provides an overview of the characteristics of the included studies.

A total of 10,198 participants are represented in this review, as well as 919 posts, 12,496 comments, and 17 Twitter accounts with 1700 tweets. Study sample sizes varied from 10 to 4174 participants. Papers included in this review spanned from 2011 to 2020 (Fig. 2). In asking what are the patterns of parental use of social media to

find health information for their children are, our review discovered the majority of quantitative studies of large social media platforms found that parents made extensive use of Facebook (10%–100%)<sup>1,21-30,32-34,57-60</sup> to access health information. Parents also commonly used Twitter (0.8%–42.9%),<sup>21,23,24,26,28,30,58,59</sup> Wikipedia (8.2%–18%),<sup>1,22,26,33</sup> and YouTube (14%–16.3%)<sup>26,28,33,57,59,60</sup> (Fig. 3). Two studies reported discussion forum use (13.1%–16%), including German medical forums<sup>26</sup> and dental forums.<sup>22</sup>

Facebook is the preferred platform for parents seeking pediatric health information, dominating other platforms from 2017, and featured twice as often as other platforms<sup>24-26,34,57,60</sup> in 2019 (Fig. 3). Facebook groups catering to parents with children with specific health concerns (e.g. Costello Syndrome, Hydrocephalus) were commonly reported, as well as geographically specified groups (e.g. an Autism Spectrum Facebook group in Malaysia).<sup>10,25,28,32-34,37,38,41,43,48,51,53,57,59</sup> These Facebook groups were shown to be the most frequent facilitator of parents' engagement with social media for health information. Some parents were also part of closed Facebook groups (where parents apply to the group's administration to join, and engagement is inaccessible to non-members).<sup>10,37,51,53</sup>

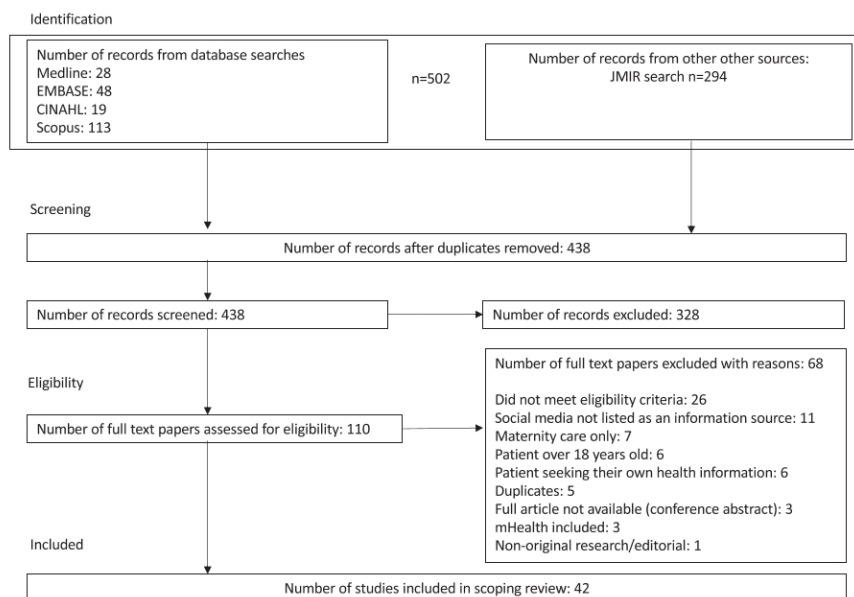
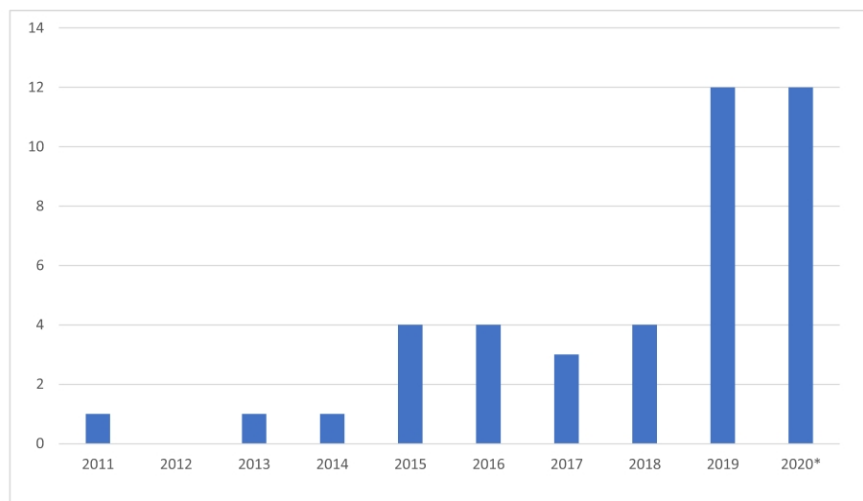


Figure 1. PRISMA- ScR flow chart.

**CHARACTERISTICS OF PARENTS WHO USE SOCIAL MEDIA FOR HEALTH INFORMATION**

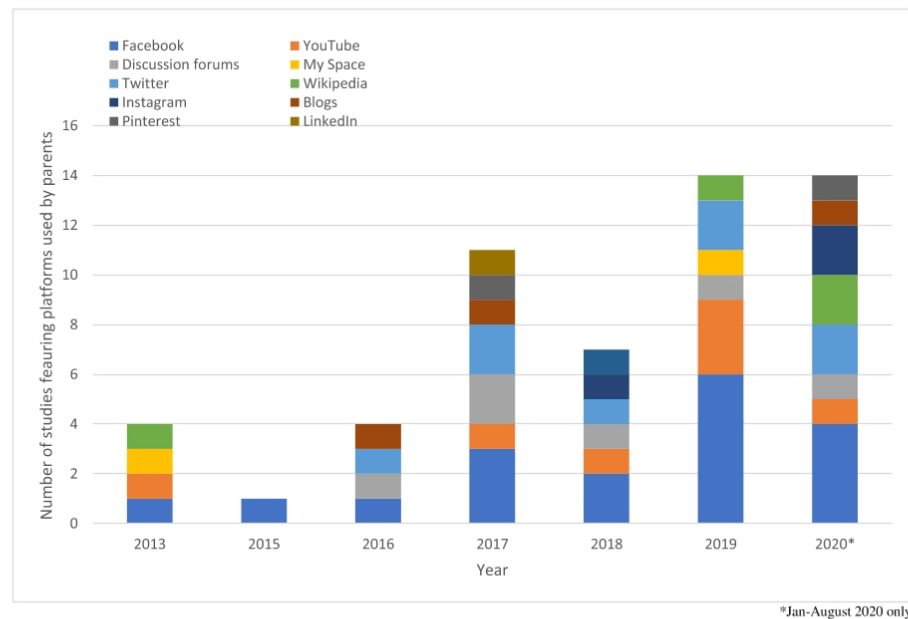
Across the nine studies reporting parents' highest qualification, between 6.3% and 52.4% of parents had

completed high school or equivalent,<sup>1,23,24,26,28,29,31-33,35,44,46-48,56,57,59</sup> while 14.2% to 78.2% had a bachelor's degree qualification.<sup>1,23,25,28,31-33,35,42,44,48,57,59</sup> A later study<sup>56</sup> found higher educational attainment was



\* Jan – August 2020 only

Figure 2. Number per year of scholarly papers featuring parents' use of social media for pediatric health information. \* Jan – August 2020 only.



\*Jan-August 2020 only

**Figure 3.** Platforms represented in quantitative studies of parents' health information seeking (2013–2020)<sup>1,21–30,32–34,57–60</sup>. \*Jan-August 2020 only.

associated with the use of social media for information, whereas studies before 2018 found a preference for social media information among parents with lower educational attainment.<sup>29,33,60</sup> A 2020 US study of informational and emotional needs of parents of newborns with Severe Combined Immune Deficiency found parents with higher levels of education were more likely to prefer social media as a source of health information ( $P = .025$ ) than those with nontertiary qualifications.<sup>36</sup> This is in direct contrast to a 2013 study that found parents who completed their education before or at the end of high school had a significant preference toward social media platforms for information in comparison to parents with tertiary qualifications ( $P = .017$ ).<sup>33</sup> Mothers with lower educational qualifications were found to use YouTube as a source of health information concerning baby care or being a new mother ( $P < .01$ ).<sup>29</sup>

Income<sup>1,23,24,28–30,33,57,58</sup> or employment status<sup>31</sup> was included as a descriptive statistic across 10 quantitative studies. Two US studies used income as a variable. A 2013 study exploring the technology preferences of caregivers of children with hydrocephalus found a preference for social media for health information was associated with living above the poverty line ( $P = 0.04$ ), being non-Anglo-Europeans ( $P = .004$ ), having a lower income ( $P = .004$ ) and having a government (income assessed) insurance policy ( $P = .005$ ).<sup>33</sup> A 2018 study of US mothers and immigrant Korean mothers to the United States did not find income to be of significance when

determining whether parents chose to use social media for health information or not.<sup>28</sup>

#### PARENTS' MOTIVATIONS FOR USING SOCIAL MEDIA AS A HEALTH INFORMATION SOURCE

Parents' motivations for using social media as a health information source were reported in 33 studies. Motivations included seeking or giving information,<sup>11,21–23,25,27,28,31–35,37,38,40,43,45,46,50–52,54,56–60</sup> seeking or giving support,<sup>1,27,35,38,40,49,50,53–56,58,60</sup> seeking or giving advice,<sup>24,38,52,54,55,57,58</sup> or seeking validation or reassurance for decisions made.<sup>48,51,54</sup> Giving support was the predominant motivation, with a 2011 content analysis study reporting 96.8% of comments supported other forum members, followed by the giving of information (29.1%), seeking of support (17.1%), and seeking information (7.7%).<sup>55</sup> Other reasons parents sought health information on social media included immediacy,<sup>10,51</sup> customization and detail of information, and convenience.<sup>51,57</sup> Engagement with social media for health information was associated with feelings of social support ( $P < .001$ ) and empowerment ( $P < .001$ ) in a study of pregnant women and mothers in the United States.<sup>32</sup>

Parents sought information prediagnosis,<sup>22,25</sup> postdiagnosis,<sup>1,21,31,33–35,43,49,50,53,54,56,58,59</sup> as well as to guide self-directed health care, either proactively<sup>24,32,37,42,45,46,55</sup> or retrospectively as a result of previous



health care being unsatisfactory<sup>38,57</sup> (Table 2). The majority of parents searched with a particular health condition in mind. Twelve studies focused on parents seeking preventive health information – 5 studies related to vaccination, one study on Sudden Infant Death Syndrome prevention and 6 studies focused on parents looking for general health information for their child, such as infant feeding,<sup>10,28,51</sup> normal bowel movements,<sup>28,48</sup> growth and development,<sup>28,48</sup> sleep,<sup>28</sup> and behavioral changes.<sup>27,48</sup> From this, one study found that some parents preferred health information from social media as they believed other parents were more educated regarding caregiving and self-management strategies than health care professionals.<sup>35</sup> Other parents used social media to access and discuss health information that would be considered peripheral to conventional medical advice, such as vaccine hesitancy information.<sup>37</sup>

#### SENTIMENTS AND PERCEPTIONS TOWARD THE USE OF SOCIAL MEDIA AS A SOURCE OF HEALTH INFORMATION

Sentiments toward using social media as a health information source differed with parents stating they had positive,<sup>10,25,27,32–35,38,48,50–53,57,59</sup> mixed<sup>37,41,54</sup> or negative sentiments<sup>1,31,45</sup> about their experiences. Perceived benefits of using social media for health information included increasing social connections (making friends),<sup>27,48,51</sup> having a safe and private place to discuss sensitive issues,<sup>27,38,51</sup> obtaining support,<sup>27,34,35,38,44,48,52</sup> gaining reassurance/validation for decisions already made,<sup>10,51</sup> and the provision of accessible, immediate and detailed knowledge based on experience from other parents.<sup>1,10,25,30,33–35,38,40,43,48,49,51,53,57,60</sup> Perceived drawbacks included finding unhelpful information about worst case scenarios (i.e. catastrophizing), information quality concerns,<sup>1,23,29,41,46,47</sup> privacy concerns,<sup>52</sup> and group sentiments sometimes misleading those seeking information.<sup>24,39</sup> Parents also described discomfort over occasional conflict between users,<sup>45</sup> leading to some parents feeling judged, maligned, or bullied.<sup>10</sup>

Benefits of using social media for health information included the normalization of challenges commonly faced by new parents, including Post-natal depression/Post-partum depression and common breastfeeding challenges.<sup>10</sup> Parents felt more educated about their child's condition<sup>59</sup> and empowered as to how best to manage it<sup>38,59</sup> as a result of accessing health information on social media, although some stated they experienced increased anxiety.<sup>59</sup> Increased self-efficacy was shown<sup>59</sup> as parents were able to come to rely less on social media health information for recurrent caregiving issues such as self-management of hydrocephalus shunt blockages<sup>33</sup> as well as the achievement of personal exclusively-expressed breastfeeding goals that were thought impossible before benefiting from social media support.<sup>38</sup> Parents who engaged with social media in a meaningful way were found to have higher perceptions of empowerment ( $P = .001$ ) and social support ( $P < .001$ ),<sup>32</sup> as well as self-efficacy ( $P < .01$ ).<sup>23</sup>

#### PARENTS' EVALUATION OF HEALTH INFORMATION FOUND ON SOCIAL MEDIA

In answering our research question concerning how parents understand health information found on social media, we identified 20 quantitative and qualitative papers examining how parents evaluate health information found on social media (i.e. health literacy skills).

##### INDIVIDUAL FACTORS THAT IMPACT PARENTS' UNDERSTANDING OF HEALTH INFORMATION FOUND ON SOCIAL MEDIA PLATFORMS

Health information sought from social media was viewed with both skepticism<sup>1,42,45,54</sup> and acceptance<sup>48</sup> by parents. Parents sought to understand and evaluate credibility using methods including examining the source,<sup>35,42</sup> translating information into their native language using Google Translate,<sup>46</sup> and assessing how the information was presented, including graphics, interactivity, use of media, and aesthetics.<sup>42</sup> Some parents chose to obtain health information directly from peer-review journals seeing this as a way of accessing credible information without media (mis)interpretation,<sup>30,41,48</sup> while others did self-styled information triangulation by crowdsourcing information and determining consensus.<sup>35,42,48,52</sup>

Many parents asked healthcare professionals to verify information found on social media.<sup>1,25,35,45,48,52,54,59</sup> Other less frequently used information validation strategies included assessing information based on gut feeling, inner wisdom, and intuition.<sup>10</sup> Confusion and misinterpretation sometimes occurred<sup>37</sup> among parents due to the complexity of information<sup>10</sup> presented, and the vocabulary used.<sup>42</sup> This could sometimes result in information overload.<sup>10</sup>

##### GROUP FACTORS THAT IMPACT PARENTS' UNDERSTANDING OF HEALTH INFORMATION FOUND ON SOCIAL MEDIA PLATFORMS

Information and knowledge based on lived experience<sup>40</sup> were much more readily accepted by parents, with the perception being underpinned by their view that parents in the same predicament were inherently trustworthy<sup>30</sup> due to the shared experience of managing children with a chronic or life-threatening illness.<sup>30,35</sup> In some cases, social media users were more trusted than health care professionals,<sup>30</sup> either by choice or by necessity, in the absence of clinical or evidence-based information.<sup>43</sup> In platform facilitated groups, information was viewed by group members as being more trustworthy if it came from more experienced members.<sup>33,38</sup>

Conflicting information found on social media was a theme reported in five studies. Discrepancies were apparent between opinions put forward by group members,<sup>41,54</sup> between group members and best practice medical guidelines,<sup>39,54</sup> or between opinions put forward by group members and specific advice given by health care professionals.<sup>25,38</sup> This resulted in confusion for users,<sup>10,25,36</sup> with 49.8% of users in one study relying on the information from their health care professional and

14.9% relying on information found on social media (of which 87% relied on information found in patient and parent Facebook groups).<sup>25</sup> In one study, the value placed on social media (Twitter and Facebook) by parents as an information source was found to have an inverse relationship with perceptions of vaccination benefit ( $P < .01$ ).<sup>24</sup>

### DISCUSSION

This review has revealed the patterns in parents' use of social media to source health information for their children, including both positive and negative aspects of this use. The characteristics of parents who use social media for health information for their children have shown interesting changes over the timespan of the included studies. While low levels of educational attainment among parents who preferred social media for health information were initially observed,<sup>29,33,60</sup> that relationship has inverted since 2018, with more parents with higher levels of education using social media to source health information.<sup>56</sup> Income also shifted as a determinant of parents' use of social media for health information. A 2013 US study showed that living above the poverty line but having a lower income and having a government income-assessed health plan was associated with using social media for health information.<sup>33</sup> The use of social media for health information for these parents may have enabled access to health information that was previously inaccessible. More recent studies have found no such relationship between income or education and parents' use of social media for health information.<sup>28</sup> This increased use of social media in higher educated parents could be explained by an age-cohort effect<sup>61</sup> and access to better technology, especially smartphones.<sup>62</sup>

When answering our second research question, we found that parents are generally motivated to use social media for health information after health care has been sought rather than when trying to determine if health care is required. This suggests parents look to other parents in the same situation for information, support, and advice about how to manage their child's health condition, along with guidance on navigating the health system and required resources. Our review also found that parents can feel positive about using social media for health information seeking because of the perceived broader social benefits that result from interactions that would not have occurred otherwise. This supports and adds context to Gage-Bouchard's finding<sup>35</sup> that parents trusted other parents more than their treating health care professionals when considering the caregiving and health management needs of the child outside the consultation room.

Our review found that parents often find it difficult to use social media to source health information and then adequately evaluate this information. Challenges included navigating, identifying, and managing conflicting information that exists because information exchange on social media occurs within a dialogue which may compound confusion by introducing layers of nuance, emotion, complexity, and influence.<sup>63</sup>

The influence of groups of like-minded people and the resulting confirmation bias cannot be overstated. Group dynamics on social media can facilitate 'echo chambers,'<sup>64</sup> which occur when only the dominant information or opinion within a group is heard, with dissenting information or opinions being minimized or excluded. This results in the same message being repeated without variation, culminating in the group members coming to view this messaging as the singular truth. This is especially prevalent within social media groups of like-minded people, such as anti-vaccination social media groups, where the group dominion repels divergent or evidence based opinions and reinforces group consensus and dominant opinions.<sup>65</sup> These groups are often influential, with ambivalent members being seen to become more agreeable to the group's ideology within a single discursive interaction.<sup>37</sup> This often occurs after other members inform them of the group's consensus on the risks of vaccinations, whether by a conversation thread or by hyperlinking to other resources.<sup>37</sup>

Echo chambers reinforce misinformation on social media<sup>66</sup> and obstruct individuals from accessing evidence-based health information. Despite this, there has been a significant increase in parents' use of social media for health information, particularly on Facebook, since 2019.<sup>67</sup> This correlates with Facebook's tweaking of their algorithm in 2019 to boost group recommendations to the top of a user's "newsfeed".<sup>67</sup> Facebook did this to create more "meaningful communities" on its platform, where like-minded people (with comparable confirmation biases) could meet and interact. It has brought with it a significant increase in user engagement,<sup>68</sup> which is Facebook's primary commodity.<sup>69</sup>

Many parents seek evidence-based health information. Their reliance on abstracts (in lieu of full journal articles) for health information<sup>70,71</sup> is one indication of the demand and need for primary, objective, evidence-based health information to be more accessible. However, while this stark information poverty<sup>43,72</sup> exists, health information available on social media, despite sometimes lacking an evidence base, may be utilized because the desired information is sequestered behind paywalls. There is also a distinct lack of alternative sources of evidence based health information that are as easily accessible, convenient and easily understood as what social media offers. Our results indicate the need to provide training on parents' use of social media for health information for future pediatric clinicians. Such training should explain how parents now routinely seek,<sup>21,22,27,28,33</sup> use,<sup>22,26,28,59</sup> and share<sup>26</sup> health information (being mindful that for some parents, social media is a preferred source of health information<sup>47</sup>). Training could also identify key medical misinformation risks,<sup>73</sup> scaffold ways to find high quality pediatric health information,<sup>48</sup> and highlight the clinician's potential to counter misinformation building on the ongoing trust in doctors and drawing on fact-checking resources.<sup>73</sup>

### FUTURE DIRECTIONS

The results of this scoping review suggest it would be prudent for clinicians to assume that many parents consult



social media after their clinical interactions to seek further health information. The information found may be used in conjunction with information provided during the clinical consult, or it may be used instead of the evidence-based information provided. Further research is needed on how best to address this via health counseling. To date, most research touching on this calls for the health literacy upskilling of patients by clinicians during their health counseling. It needs to be acknowledged that health care professionals are often not in the position to give parents the appropriate health media literacy training that would be needed to effectively combat social media misinformation. As such, innovative tools to help parents navigate to reliable health information are urgently needed to minimize the potential impacts of medical misinformation on children's health.

#### LIMITATIONS

Due to the selection strategy, potentially relevant articles on parents' use of social media alongside their use of Internet and mHealth apps may have been excluded. The effects of specific social media and other internet sources require more disentangling than is possible here because study designs often lack separation of parental source choices. While it was beyond the scope of this review to analyze research in languages other than English, it is acknowledged the issue transcends geographical borders.

#### CONCLUSIONS

Current data show that parents are increasingly using social media for health information needs, as it facilitates the exchange of timely and tailored information and enables significant social support between users. However, social interaction can facilitate the exchange of opinion masquerading as factual information. Despite parents' best efforts, the current information terrain does not lend itself to effective information seeking. Social media's unique challenges need to be urgently analyzed to enable the development of effective health literacy education to promote safe and effective social media navigation for health information seeking.

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#### SUPPLEMENTARY DATA

Supplementary data related to this article can be found online at <https://doi.org/10.1016/j.acap.2021.12.006>.

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## 2.4 Chapter Conclusion

This chapter presented a scoping review of 42 articles exploring parents' use of social media for health information for their children. This review found that parents have many motivations to use social media for health information, including seeking information, giving information to other parents, finding and giving support and seeking validation for health decisions made. Parents also valued the lived experience of other parents going through the same health journey as themselves for both health information pertaining to their child and for support for themselves, which lent itself to the formation of a community not available anywhere else. Aspects of social media that made this possible include its immediacy, simultaneous synchronicity and asynchronicity, convenience, and the customisation and detail of the information found.

The following chapter presents the methodology and methods for this thesis, as well as the theoretical framework and rationale for choosing a mixed methods approach for investigating this phenomenon.

## 2.5 References

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## Chapter 3 – Methodology and Methods

### 3.1 Introduction

This chapter will outline this doctoral project's methodology, including the philosophical, epistemological, and ontological stances. It will also discuss the rationale and considerations for choosing mixed methods for this research.

The theoretical frameworks for this research will be explored, including phenomenology and Triadic Reciprocal Determinism, to explain how this research was framed in order to make sense of it.

This chapter will describe the methods used, with each research design explored in detail. Detailed summary tables highlighting the important data from each corresponding results chapter are included.

### 3.2 Methodology

#### 3.2.1 Theoretical underpinnings: A philosophical perspective

A philosophical perspective, also known as a paradigm or worldview, is “a basic set of beliefs that guide action” (Guba, 1990). Using a parallel-database variant convergent mixed methods research design (Creswell & Plano Clark, 2018), underpinned by a pragmatic philosophical perspective, this thesis explores the depth and breadth of the observed phenomenon of parents using social media for health information for their children.

A scoping review was conducted to map out the extant research internationally but also to draw out common themes (Arksey & O'Malley, 2005; Peters et al., 2015; Tricco et al., 2016). Quantitative data was collected to explore the breadth of common experiences between parents within the Australian context. Qualitative data was collected to understand the depth of the lived experience of individual parents within the Australian context.



The pragmatic approach allowed the researcher to be reflexive and responsive to the data, connecting it to theory before, during and after data collection in an abductive way (Morgan, 2007). It also allowed for the researcher to be flexible and responsive in the research design when logistical challenges presented themselves, but also when the data was collected and the layered understanding of the phenomenon was being developed iteratively throughout the research (Morgan, 2007).

Pragmatism lends itself particularly well to mixed methods research being a compromise between empiricism and rationalism (Moon & Blackman, 2014). While some schools of thought consider that the underpinning paradigms of quantitative and qualitative research are diametrically opposed such that they cannot be combined, it could be said that pragmatism is the perfect philosophical underpinning for mixed methods, as neither is committed to one philosophical position, but both are instead problem-focused, using whatever methods are needed to understand the problem at hand (Creswell, 2009; Moon & Blackman, 2014), resulting in a broad and inclusive approach to new knowledge (Morgan, 2007).

### 3.2.2 Epistemological and ontological stance

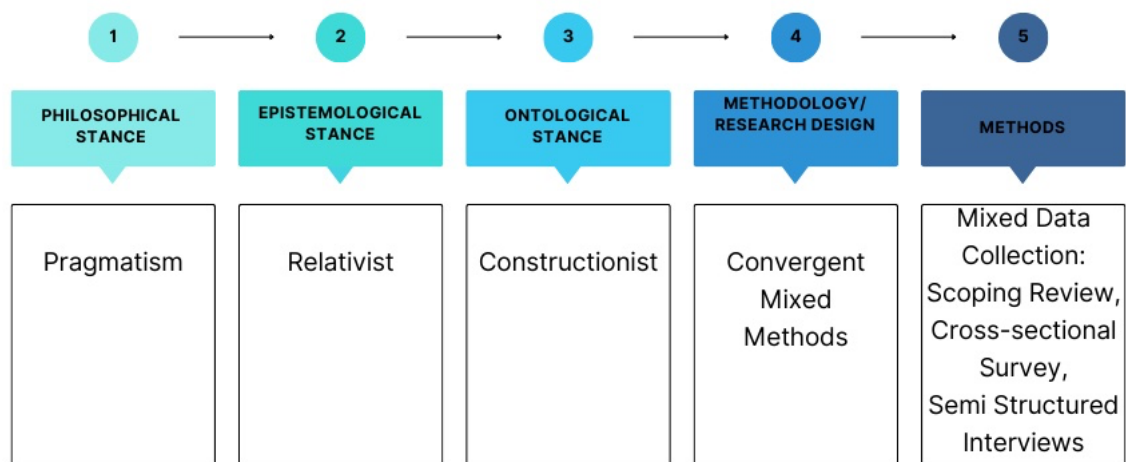
Epistemology is the understanding of how knowledge is acquired, while ontology refers to how an individual makes sense of the world around them and their reality.

Constructivism as an epistemological stance is the view that “all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world and developed and transmitted within an essentially social context” (Crotty, 1998 p.42). Constructivism as an epistemological school of thought states that knowledge is for each human to subjectively construct as they engage with the world (Crotty, 1998). based on their cultural, historical and social perspectives (Crotty, 1998; Moon & Blackman, 2014).

Ontologically, how a person makes sense of the world – their reality based on interpretations that construct their individual perspectives and beliefs – pairs with a relativist position (Crotty, 1998). Relativism states that knowledge is not a universal truth to be actively sought out and objectively acquired (Crotty, 1998) but is relative to the experiences that one has as a by-product of living one’s life (Moon & Blackman, 2014).

In combination, constructivist epistemology and relativist ontology positions result in the stance that meaning comes from within individuals, influenced by social interactions between individuals and their lived experience of navigating the world they live in.

Figure 3.1 Mixed methods research study design



Adapted from (Biesta, 2010)

### 3.3 Mixed Methods Research Design

Mixed methods research combines quantitative and qualitative data in a research study (Creswell & Creswell, 2018, p. 4) to achieve both “breadth and depth of understanding and corroboration” (Johnson et al., 2007, p. 123). By synergistic effect, mixed methods methodology provides “the most informative, complete, balanced and useful research results” (Johnson et al., 2007, p. 129) that are not available when using

quantitative and qualitative methods alone. The study design of the mixed methods research in this thesis is summarised in Figure 3.1.

Figure 3.1 Mixed methods research study design






The main strength of mixed methods is that as a research method, it minimises the individual weaknesses of the methods employed while simultaneously maximising the strengths of those same methods by synergistic effect (Creswell et al., 2011). It also allows for multiple perspectives when investigating phenomena, providing a more complete and detailed understanding, which wouldn't be possible with one method alone (Creswell et al., 2011).

To best use mixed methods, considering a project's purpose and what the data will be required to do should guide what methodology is used (Creamer, 2018). This was first asserted by Greene, an early adopter of mixed methods, who proposed a typology of purposes for mixed methods (Figure 3.2) for researchers to be able to determine which methodology to use based on the purpose of the research they are undertaking. (Greene et al., 1989).



Figure 3.2 Purposes of mixed methods in research design

**PURPOSES OF MIXED METHODS IN RESEARCH DESIGN**

		Purpose	Rationale
	<b>TRIANGULATION</b>	Triangulation seeks convergence, corroboration, and correspondence of results from different methods.	The primary goal of triangulation is to increase the validity of results by counteracting the variance in irrelevant sources due to bias.
	<b>COMPLEMENTARITY</b>	Complementarity seeks elaboration, enhancement, illustration, and clarification of the results from one method with the results from the other method.	Interpretability is increased, as well as meaningfulness and validity by capitalizing on the inherent strengths of different methods, while counteracting their biases.
	<b>DEVELOPMENT</b>	Development seeks to use the results from one method to help develop or inform the other method.	The aim of development is to increase the validity of results by capitalising on the inherent strengths of the methods used.
	<b>INITIATION</b>	Initiation seeks the discovery of paradox and contradiction, new perspectives of frameworks, with the recasting of questions or results from one method with questions or results from the other method.	The objective is to increase the breadth and depth of inquiry results and interpretations by analysing them from the different perspectives of different methods and paradigms.
	<b>EXPANSION</b>	Expansion involves extending the breadth and range of inquiry by using different methods for different components of inquiry.	The goal is to increase the scope of inquiry by selecting methods most appropriate for each component.

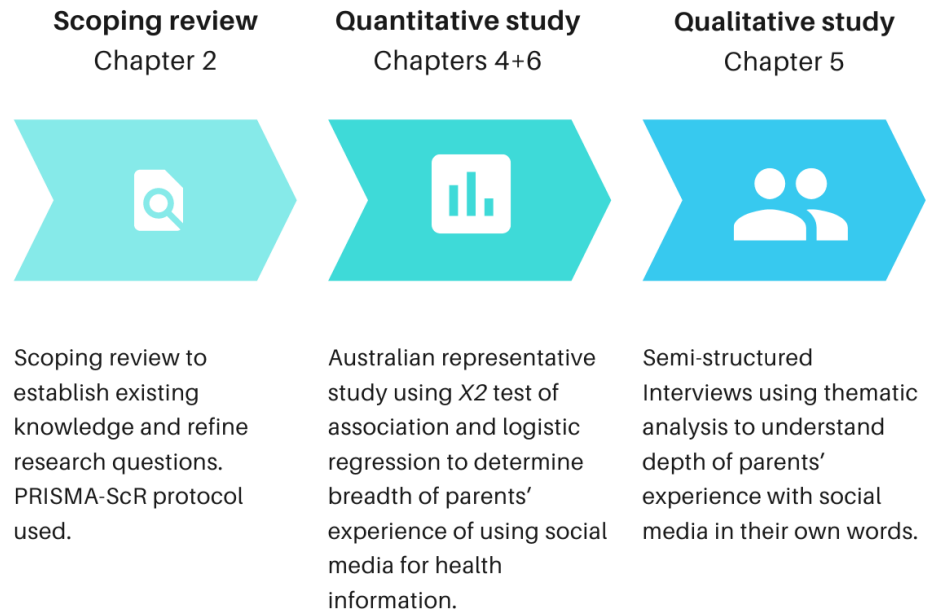
Adapted from: Greene, J.C. Caracelli, V.J. Graham, W.F. (1989) Toward a Conceptual Framework for Mixed-Method Evaluation Designs. Educational Evaluation and Policy Analysis. Table 1, P.259

Mixed methods were chosen for this research after considering the research objectives to obtain a comprehensive baseline of understanding of the phenomena being investigated. As this is a social science area of research where the researcher wanted to explore and understand the human lived experience of this phenomenon on an intrapersonal, interpersonal, and extra-personal level, mixed method is an ideal choice of methodology. The researcher was able to explore the breadth of lived experience across a representative population sample by using quantitative methods, in this case, an Australian representative cross-sectional survey. Additionally, the use of qualitative methods (semi-structured interviews) enabled the researcher to deep dive with individuals about their personal lived experience, expanding and adding dimension to the quantitative inquiry, whilst also triangulating with the qualitative data. The scoping review conducted was the foundation for both the quantitative and qualitative inquiry.

This research uses a convergent mixed methods design with a quantitative focus (QUAN + qual) (Creswell & Plano Clark, 2018, p. 63). The research was undertaken in

three phases: (1) a scoping review, (2) a representative quantitative survey, and (3) qualitative semi-structured interviews (Figure 3.3).

Figure 3.3 Research phases in this thesis



### 3.4 Theoretical Framework

The word 'theory' has its origins in the Greek word *theōrein*, which means "to consider, speculate, look at" (Harper, 2022). A theory allows us to systematically approach the phenomena that we are seeking to understand (Alvesson & Sandberg, 2023) by looking at, considering, identifying, analysing, and defining the patterns and central relationships between variables that are characteristic of the phenomenon being studied (Hochbaum et al., 1992). From this theoretical position, we can predict outcomes of the same phenomenon that occur in different circumstances (Hochbaum et al., 1992; Rimer et al., 2005 p.4).

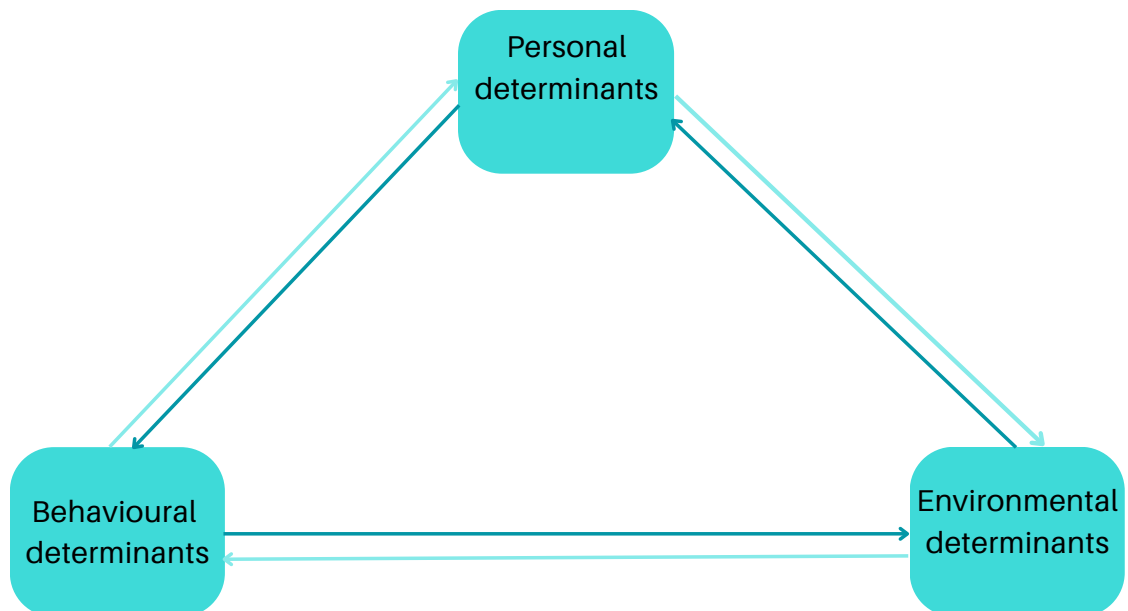
Within health, and especially on a population level, explanatory theories are seen to be particularly insightful (Rimer et al., 2005, p. 4). There are multiple layers of human behaviour to understand and consider when exploring and explaining a new phenomenon, such as this doctoral research's focus. Albert Bandura's Triadic Reciprocal Determinism (Bandura, 1986) theory was chosen for this research due to its

simplicity, timelessness, and relevance – whilst also being able to hold within it all the complexity of social media, despite being developed decades before social media.

### 3.5 Albert Bandura – Triadic Reciprocal Determinism (1986)

Contrary to the popular behaviourist and humanist theories at the time, Bandura’s Triadic Reciprocal Determinism (TRD) theory (as part of his larger Social Cognitive Theory (SCT) (Bandura, 1986)) was developed to explain how every individual is influencing while simultaneously being influenced by personal, behavioural and environmental determinants, in a reciprocal relationship, at any given time (Figure 3.4). These factors are dynamic and interconnected, with the intricate relationship between each shaping human behaviour (Bandura & Cervone, 2023, p. 9). For this thesis, three corollary dimensions are Intrapersonal Determinants (personal factors), Interpersonal Determinants (behaviours), and Extra-personal Determinants (environment) to align with the person-centred approach of the thesis.

Figure 3.4: Albert Bandura’s Triadic Reciprocal Determinism



Adapted from (Bandura & Cervone, 2023, p. 9)

### 3.5.1 Intrapersonal determinants

Intrapersonal determinants (which Bandura refers to as personal determinants (Bandura & Cervone, 2023, p. 9) include a person's internal characteristics and factors that influence their behaviour. These can include, but are not limited to, a person's goals, values, self-efficacy, and cognitive processes such as memory, attention, and decision-making. All these factors play a crucial role in shaping how individuals interpret and respond to their environment whilst also guiding their behavioural choices.

### 3.5.2 Interpersonal determinants

Interpersonal determinants (which Bandura referred to as 'behavioural determinants' (Bandura & Cervone, 2023, p. 9)) refer to the observable actions, responses, and patterns of conduct that an individual exhibits in any given situation. These actions are not solely determined by intrapersonal determinants but also by extra-personal determinants, together interacting at the same time, resulting in the behaviour exhibited. It is through interpersonal determinants that an individual actively engages with their surroundings, enact their beliefs and intentions, and shape their environment.

### 3.5.3 Extra-personal determinants

Extra-personal determinants (which Bandura referred to as 'environmental determinants' (Bandura & Cervone, 2023, p. 9)) encompass the external context in which individuals operate, including social, cultural, and physical factors. This includes social influences from family, peers, and media, as well as situational factors such as societal norms, traditions, rituals, policies, and laws. The environment provides the context within which behaviour occurs and exerts significant influence on individual actions and decisions. With this in mind, Bandura's theory offers a practical framework for understanding how parents use social media for health information for their children, as social media is a powerful extra-personal determinant with the capacity to influence behaviours that can be health-enhancing or damaging to a child's health.

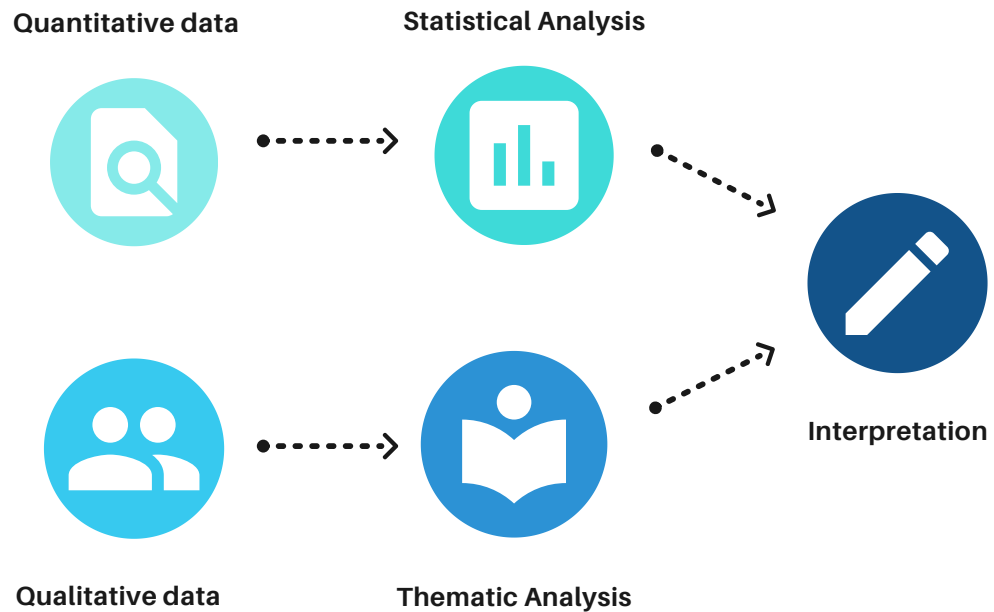
Alongside contributing to the external environment, health information accessed via social media can shape intrapersonal determinants by the provision of new, influential, and socially endorsed health information, which may be adopted by parents using social media (Bandura, 2001, p. 288). Interaction between parents has the ability to influence and drive change in a parent's interpersonal determinants (Bandura, 2001, p. 291). This includes interactive networks such as the social media (Bandura, 2001, p. 292), where otherwise unacquainted people are brought together in a shared environment (Bandura, 1982, p. 752). Media effects on health knowledge and behaviour – both beneficial and harmful – are well documented in the literature (Chapman et al., 2005; Noar et al., 2015), but how exactly parents are influenced, and the type and extent of social media influence on parents is under-researched, a paucity this study is designed to address.

## 3.6 Methods

### 3.6.1 Convergent mixed methods research design

A convergent mixed methods design (Figure 3.5) is when qualitative and quantitative data are collected simultaneously so as to triangulate the data when analysed (Creswell & Plano Clark, 2018). Specific to this thesis, the use of qualitative semi-structured interviews and the quantitative cross-sectional survey allowed the researcher to gain both a depth and breadth of understanding that wouldn't result from using these methods individually.

Figure 3.5 The convergent design-parallel database variant (adapted from Fig 3.3 Creswell and Plano-Clark 2018 p.66)



The mixed methods parallel database variant was used because of the challenges of having different cohorts participate in each phase of data collection. The parallel database variant allows for two types of data to examine facets of the same phenomenon, with the databases being analysed independently with the data synthesised at the interpretation stage rather than at the analysis stage (Creswell & Plano Clark, 2018). Due to extensive Covid-19 lockdowns in Sydney and across Australia, pivoting to a parallel-database variant convergent study design meant that the doctoral researcher was able to collect data opportunistically, capitalising on the brief periods where restrictions were eased, without compromising any of the rigour and integrity of the original convergent mixed methods study design (Creswell & Plano Clark, 2018).

### 3.6.2 Scoping review

A scoping review is a form of evidence synthesis that aims to map the “volume, nature and characteristics” of published research (Arksey & O’Malley, 2005, p. 23) and to “identify the main concepts, theories, sources and knowledge gaps” of extant

literature in any given field (Tricco et al., 2018, p. 267). The scoping review reporting was guided by a 22-item Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist to ensure consistency in the methodological and reporting quality (PRISMA, 2021).

Scoping reviews can be conducted to meet a range of objectives simultaneously which is why it was chosen for this research. The scoping review process allows the researcher to set eligibility criteria for inclusion and exclusion to maintain the scientific rigour and validity of the study (Tricco et al., 2016). The doctoral researcher chose to include only peer reviewed research to limit the need to assess the quality of the literature itself as part of the review process. This in turn expedited the completion of the review.

Secondly, as this is a novel area of research with scant scholarly literature concerning the general population, the scoping review methodology allows for the research across disciplines and methodologies to be mapped and knowledge gaps to be identified quickly, all to underpin future research (Peters et al., 2015). This was particularly useful as the research area was becoming more clinically relevant and broadly of interest as the COVID-19 pandemic was progressing and as social media was becoming (more) prominent as a source of health information, particularly regarding COVID-19 vaccinations and health measures.

Lastly, scoping reviews allow for broader questions to be answered (Tricco et al., 2016). With a dearth of existing literature to explore, a general overview of the research area was sought, rather than attempting to answer any questions on a granular level, which would be more appropriate for traditional systematic review that a large cache of literature would support.

### 3.6.3 Scoping review protocol

The PRISMA-ScR approach was chosen (PRISMA, 2021) for this literature review due to the heterogeneity of study designs being included, the variety of variables being investigated (such as the platforms used by our population and the health issues parents sought information for), and this being a relatively new area of study (Arksey & O'Malley, 2005; Tricco et al., 2018). PRISMA-ScR allows for flexibility at the same time as preserving rigour when mapping extant literature (Peters et al., 2015) whilst allowing us to identify future research directions (Arksey & O'Malley, 2005; Levac et al., 2010).

The Joanna Briggs Institute Manual of Evidence Synthesis (Aromataris & Munn, 2020) guided a review protocol that was developed (but not registered) *a priori*, using the SUMARI protocol template (JBI, 2024). The reporting of the scoping review was done in compliance with the PRISMA-ScR extension checklist (Tricco et al., 2018).

The inclusion and exclusion criteria were decided *a priori*. Criteria for inclusion were peer-reviewed scholarly research (published in English) that examined parents with a child aged between 0 and 18 years of age that specified social media as a source of health information. (N.B. The term 'parent' is used here as an all-inclusive term, encompassing biological and non-biological caregivers responsible for the health decisions of a dependent child younger than 18 years).

Criteria for exclusion were any peer-reviewed scholarly research published in English that included parents of children over 18 years of age concerning pregnancy/prenatal care or included children under the age of 18 years seeking their own health information. Also, studies on mHealth were excluded along with studies that did not clearly differentiate the use of the Internet from that of social media.

Embase, Scopus, CINAHL, and Medline databases were searched on 30 August 2020, with identical but translated search strategies developed in consultation with an Information Services Librarian. A targeted search of the Journal of Medical Internet Research (JMIR) through PubMed (journal specified) was also conducted on 22



September 2020, as it was thought that many of the peer-reviewed scholarly articles that were being targeted would likely be published there. All peer-reviewed empirical research was included, with all other search results being excluded to limit bias which is known to be inherent in editorials based on opinion and lack of peer review for conference abstracts. To control for quality and impartiality (Hwang & Shah, 2019), grey literature (literature that is produced by governments, academics, businesses and industry but is not formally controlled or published by publishing houses) was excluded.

#### 3.6.4 Search terms

The search terms used were:

##### **Scopus search – 30 August 2020**

("Social Media" OR Facebook OR Twitter OR YouTube OR Wechat OR Pinterest OR Instagram OR "online social networks" OR Reddit OR Whatsapp OR "Facebook messenger" OR Snapchat OR TikTok OR QQ OR QZone OR Sina Weibo OR Kuaishou) AND Health AND ((information OR consumer) W/3 ( behavior#r\* OR seeking OR engagement OR need\*)) AND (Parent OR caregiv\* OR guardian OR father OR mother OR carer).

**Results: 113**

##### **Medline search – 30 August 2020**

(Social media or facebook or Twitter or Youtube or Wechat or Pinterest or Instagram or "online social networks" or Reddit or WhatsApp or messenger or snapchat or tiktok or QQ or Qzone or "Sina Weibo" or Kuaishou).tw. or Social Media/ and Health.tw. or exp Health/ and (((information or consumer) adj3 (behavior?r\* or seeking or engagement or need\*)).tw. or Consumer Health Information/ or Information Seeking Behavior/) and consumer health information/ or information seeking and (parent\* or carer\* or caregive\* or father\* or mother\* or guardian\*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms].

**Results: 28**

### **EMBASE search – 30 August 2020**

(Social media or facebook or Twitter or Youtube or Wechat or Pinterest or Instagram or "online social networks" or Reddit or WhatsApp or messenger or snapchat or tiktok or QQ or Qzone or "Sina Weibo" or Kuaishou).tw. or Social Media/ and Health.tw. or exp Health/ and ((information) ADJ3 (seek\* OR evaluat\* OR apprais\* OR assess\*)) and (parent\* or carer\* or caregiver\* or father\* or mother\* or guardian\*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms].

**Results: 48**

### **CINAHL search – 30 August 2020**

( TI facebook OR AB facebook ) OR ( TI twitter OR AB twitter ) OR ( TI YouTube OR AB YouTube ) OR ( TI WeChat OR AB WeChat ) OR ( TI instagram OR AB Instagram ) OR ( TI Pinterest OR AB Pinterest ) OR ( TI Reddit OR AB Reddit ) OR ( TI "online social networks" OR AB "online social networks" ) OR (MH "Social Media+") AND ( TI health OR AB health ) OR (MH "Health+") AND ( ((information OR consumer) ADJ3 ( behavio?r\* OR seeking OR engagement OR need\*)).tw ) OR (MH "Consumer health information") OR (MH "Information seeking") AND TX mother OR TX father OR TX guardian OR TX carer OR TX caregiver OR TX parent\*.

**Results: 19**

### **PUBMED (JMIR) search – 22 September 2020**

"((((("health information") AND (((("J Med Internet Res"[jour])) AND (((parent\*) OR (father\*)) OR (mother\*)) OR (care\*))) AND (((("Web 2.0") OR ("social media"))),,,"health information"[All Fields] AND ("J Med Internet Res"[Journal] AND ("parent\*"[All Fields] OR "father\*"[All Fields] OR "mother\*"[All Fields] OR "care\*"[All Fields])) AND ("Web 2.0"[All Fields] OR "social media"[All Fields])).

**Results: 294**

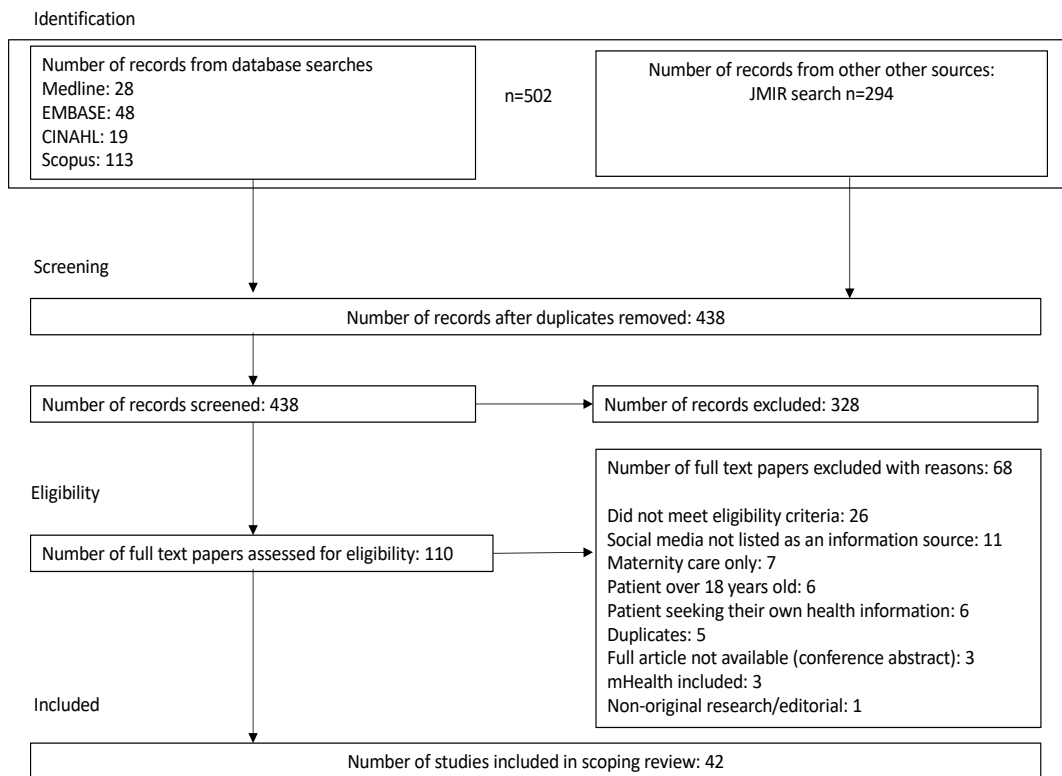
The date filters were left open, as social media we wanted to be able to include every single relevant article across the lifespan of social media that was relevant to our search. The initial search resulted in 512 journal articles.

The search results were exported into Covidence (*Covidence Systematic Review Software*, 2021), where the screening process was guided by the scoping review

protocol. Duplicates were removed (74 excluded). Two reviewers (the doctoral student and a collaborator) screened all papers in 2 stages – initially by title and abstract (328 excluded), and then by full paper to assess eligibility for inclusion, according to the eligibility criteria (68 excluded). Inconsistencies were discussed between the two screening reviewers. Two papers that could not be resolved between the two screening reviewers were referred to the entire authorship team for discussion as to eligibility, resulting in one paper being included and one paper being excluded. Studies that appeared in records more than once were collapsed into a single unit (first study published) for the purposes of analysis. The PRISMA-ScR process resulted in 42 eligible papers being included in the scoping review.

The data were extracted based on the participant (primarily demographics), concept, context, and metadata in an iteratively adjusted data extraction tool. Concept data extraction focussed on data needed to directly answer the research questions – such as parents' behaviour, motivation, and sentiment related to social media use for health information. Self-reported outcomes (what parents did with or as a result of the health information they found on social media) were also extracted to provide additional insights. Context data extraction focussed on study methodology and setting, including the country in which the study was conducted, the data collection methods and study designs used, the year of data collection, and the social media platforms investigated. Finally, the study data extracted was related to the metadata needed to inform the review. Once data extraction was completed, data synthesis was initiated on Microsoft Excel, utilising data filters to dynamically group studies together that had similarities, depending on the data point being explored at the time. Data were then mapped to allow for comprehensive analysis and cohesive results. The article eligibility selection process is illustrated in the PRISMA-ScR flow chart below (Figure 3.6). Reporting was guided by the PRISMA-ScR Checklist (Appendix A).

Figure 3.6 The PRISMA-ScR flow chart



An overview of the study is also provided (Table 3.1).

Table 3.1 Overview of the study - scoping review

Study design element/ consideration (adapted from Creswell 2013, Ch7)	How this was done in this Scoping Review (refer to Chapter 2 for full description of methods in publication)
<b>A. Research Design</b>	
Data collection activity	Literature review
Decide on the research questions	<ol style="list-style-type: none"> <li>1. How do parents use social media to find health information for their child?</li> <li>2. What motivates parents to engage with social media to find health information for their child?</li> <li>3. How do parents seek to understand and evaluate the health information they find and how does social media impact parental health information seeking?</li> </ol>
Nature of data to be collected	Published peer review articles
<b>B. Sample Design – on paragraph</b>	
Identify articles	<p>PRISMA flow chart (above)</p> <p>Inclusion criteria: Parents of children 0-18. Social media specified as a health information source</p> <p>Exclusion criteria: mHealth, teenager seeking their own information, teenage parents</p>
Sample parameters	<p>Date filters open</p> <p>Empirical, peer reviewed articles only</p>
Determine type of literature review	Scoping Review
<b>C. Data Collection</b>	
Database Information Sources	Embase, Scopus, CINAHL, Medline, JMIR specific search on Pubmed
Search Strategy	Developed with University of Technology Sydney Information Services Librarian
Selection of sources	Meet inclusion and exclusion criteria
Data charting process	Covidence. 2 reviewers. Group consensus.
Data items	Findings
<b>D. Results</b>	
Characteristics of sources of evidence	Peer-reviewed journal articles
Results of sources of evidence	Study characteristics. Characteristics of parents who use social media for health information. Parental motivations for using social media as a health information source. Sentiments and perceptions towards the use of social media as a source of health information. Parents' evaluation of health information found on social media. Group factors that impact parents' understanding of health information found on social media platforms.
Synthesis of results- analysis method	Based on data extraction tool – Participant data, concept data, context data, and metadata.
<b>E. Discussion</b>	
Summary of evidence	Positive and negative aspects of social media use. Preference for social media after health care professional consultation. Difficulty using social media to source health information. Group dynamics and influence. Health information poverty.
Limitations	English language research only. Included papers that only included social media.
Conclusions	Identification of knowledge gap for thesis: Australian parents use of social media for health information for their children.
Funding	None

### 3.7 Quantitative Study - Cross-sectional Survey

A cross-sectional survey is a specific form of observational study design (Setia, 2016) conducted at one specific point in time. As such, they are often referred to as 'snapshot' studies about the populations that they gather data about. Surveys allow researchers to gather a breadth of data across a population to detect prevalence and patterns that are not possible using individual data (Jones et al., 2013). Stratified surveys are more robust and powerful (Australian Bureau of Statistics, 2023b), being designed so that the sample population that is surveyed is representative of the entire population that they are a sub-section of, allowing for (cautious) inferences to be made about the phenomena being researched (such as the prevalence of the phenomena across the entire population).

Cross-sectional surveys are excellent for understanding how an experience has impacted a population up until the point at which the survey is administered. They are time and cost-efficient, allowing for results to be made available more quickly than other methods (Australian Bureau of Statistics, 2023c). Surveys are also useful for coming to understand how a health service or aspect of care that has been provided has been received by the respondent, where the outcome has been experienced and won't change (Australian Bureau of Statistics, 2023c).

However, the positive aspects of this method are contrasted by the drawbacks. Bias is a significant confounder in surveys as people answer according to how they understand the question, interpret it, and relate it to their lived experience (Jones et al., 2013). Survey questions can also be ambiguous or leading if not written with care, therefore limiting the accuracy of the resulting data (Australian Bureau of Statistics, 2023a).

With these factors considered, a cross-sectional survey design was chosen for this doctoral thesis research. It provides a quantitative, broad, and overarching perspective as to the phenomena being researched, with the 1000 survey responses being stratified, allowing for the representativeness of all parents of children aged 6 months to 5 years in Australia.

### 3.7.1 Inclusion and exclusion criteria

To meet inclusion criteria, a “parent” was defined as anyone who was a biological parent, adoptive parent, or court-appointed guardian or caregiver of a child aged between 6 months and 5 years. Parents also needed to have an active social media account to meet inclusion criteria. Exclusion criteria included poor command of English and being a non-citizen or non-permanent resident of Australia. Response bias that can limit representativeness of surveys was addressed by the large sample size and the statistical power of the survey sample.

### 3.7.2 Data collection

The survey was conducted online between November and December 2021 among Australian parents of children aged 6 months to 5 years. A market research company – Quality Online Research (QOR)(Quality Online Research, 2022) – was contracted to recruit the participants, collect the data and clean the data before returning it to the researchers for analysis.

### 3.7.3 Survey tool

The 47-item survey was drawn together with questions from two previously validated surveys (Baumann et al., 2020; Frawley et al., 2020) and questions informed by findings from the previously conducted scoping review. Two validated scales were included: the Parenting Plus Skills Index (PPSI)(Ayre et al., 2020) to measure parenting literacy in an Australian context and the Critical Thinking Disposition Scale (CTDS) (Sosu, 2013) to measure the participant’s predisposition to critical thinking.

The PPSI is a 13-item validated scale that measures a parent’s ‘functional, communicative and critical health literacy’ (Ayre et al., 2020) within the Australian context. It includes questions that have both textual and visual stimuli (Figure 3.7) and requires literary and mathematical skills that are commonly encountered by Australian parents. It is scored on a continuous scale, with 0 being low and 13 being high health literacy.

Figure 3.7 Examples of questions from the Parenting Plus Skills Index

12. You go to the BabyCenter website ([www.babycenter.com.au](http://www.babycenter.com.au)), a website with information for new parents. On the 'About us' page the website says that the information on the website is reviewed by 'medical advisors.'

Does this mean it is reviewed by medical professionals (e.g. qualified doctors, nurses or other health care providers).

- Yes, definitely       **No, not necessarily**

Look at the box of children's paracetamol:

**USE CHILDREN'S PARACETAMOL BABY DROPS FOR**  
 Fast effective temporary relief from fever and pain associated with:

- Teething
- Headache
- Immunisation
- Cold & Flu symptoms
- Earache

**HOW TO USE CHILDREN'S PARACETAMOL BABY DROPS**

- Please read and retain the carton
- Shake the bottle well
- Use the measuring device provided to accurately measure
- Measure correct dose based on the table below
- Calculate the correct dose based on the child's weight. If weight is unknown, use the child's age.

AGE	AVERAGE WEIGHT	DOSE
1-3 Mths	4-6 kg	0.6-0.9 mL
3-6 Mths	6-8 kg	0.9-1.2 mL
6-12 Mths	8-10 kg	1.2-1.5 mL
1-2 Yrs	10-12 kg	1.5-1.8 mL

- Repeat 4-6 hourly if required (maximum 4 times within 24 hours)
- Can be given with water or fruit juice if preferred by your child

8. Your 2-month-old child who weighs 4kg has a fever. What dose should you give the child?

- 0.6-0.9mL**       0.9-1.2mL       1.2-1.5mL       1.5-1.8mL

9. Your 4-month-old child has a fever. She weighs 9kg. What dose should you give the child?

- 0.6-0.9mL       0.9-1.2mL       **1.2-1.5mL**       1.5-1.8mL

10. Your baby took the first dose of medicine at 10am. What is the earliest time that they can have another dose?

- 4pm       **2pm**       12pm       10.30am



The CTDS (Sosu, 2013) is an 11-item scale that comprises two subdomains: Critical Openness with seven items (score range 7-35) and Reflective Scepticism with four items (score range 4-20). It is also scored by adding the subdomain scores together for an overall critical thinking score (score range 11-55 points).

Overall scores between 11 and 34 indicate a low critical thinking disposition, 35-44 a moderate disposition and 45-55 a high disposition.

### *3.7.3.1 Demographics*

Data collected for demographics included gender, marital status, level of education attained, language spoken at home, country of birth, age, number of children and state/territory of residence (including metro, regional or rural designation) information.

The postcodes that participants provided were used to determine the Australian Bureau of Statistics Socio-Economic Indexes for Areas (SEIFA)(Australian Bureau of Statistics, 2018b). In particular, the Index of Relative Socio-economic Advantage and Disadvantage (IRSAD) (Australian Bureau of Statistics, 2018a) was used to as a socio-economic measure for each participant. Some missing postcode data (26/1000, 2.6%) were observed, potentially due to participant error, and as such, they were regarded as missing variables in the analysis.

Parents were offered a small incentive to participate (approximately AUD2.80), with a total of 1000 Australian parents satisfactorily completing the survey.

### *3.7.3.2 Parenting Plus Index Scale (PPSI)*

Parents were asked to complete a validated health literacy scale as part of their participation. The 13-item PPSI (Ayre et al., 2020) was chosen as it assesses a parent's health literacy skills regarding caregiving skills for children 0-15 within an Australian context. It encompasses activities such as interpreting the NSW Immunisation Schedule and medication labels and performing simple mathematical operations in various caregiving contexts.

### 3.7.3.3 *Critical Thinking Disposition Scale (CTDS)*

Parents' critical thinking was assessed with the 11-item, 5-point Likert scale, CTDS (Sosu, 2013). The scale consists of two sub-scales measuring Critical Openness (CTDS-CO) (e.g. *I am often on the lookout for new ideas*) and Reflective Skepticism (CTDS-RS) (e.g. *I often think about my actions to see whether I could improve them*), which combined give a total score for a respondent's critical thinking disposition. Critical Openness is defined as being open to new ideas but critically evaluating the ideas and modifying one's previous thinking in light of new evidence. Reflective Skepticism is defined as learning from one's past experience and questioning evidence in light of that past experience (Sosu, 2013).

It was decided to incorporate both the parental health literacy scale and the critical thinking scale to determine if a parent's choice to use social media for health information had any association with their health literacy, their critical thinking skills, or a combination of both.

### 3.7.3.4 *Data analysis*

The survey underwent refinement and pilot testing involving 122 participants for formatting validation and quality control. Subsequent to quality assurance checks conducted by the researchers, the survey was in the field from November to December 2021, garnering 1000 eligible responses within 16 days.

IBM SPSS Statistics for Mac v.28 was used for data analysis. Initially, descriptive statistics were compiled to summarise the demographic characteristics and platform utilisation of the participants. Chi-squared tests were employed to explore potential associations between parental demographics and platform use. Logistic regression (adjusted for gender, SEIFA [IRSAD], marital status, level of education, language spoken at home, country of birth and age) was used also to investigate any determinants or predictors for the questions answered. Statistical significance was  $p < 0.05$  for the most parsimonious model.

An overview for the quantitative study is provided below (Table 3.2)

Table 3.2 Overview of the study - quantitative study

Survey design element/ consideration (adapted from Creswell)	How this was done in this quantitative research (refer to Chapters 4 and 6 or full description of methods as outlined in publications)
<b>A. Conceptualisation (or research design)</b>	
Defining the study population	Parents of children aged 6 months -5 years
Defining the outcome (dependent) variables of interest and important classifications or independent variables	1. What is the prevalence of parents using social media for health information pertaining to their child and their general health and development? 2. What is the prevalence of parents using social media to guide health decisions for their children when determining whether to seek health care for their child and what are their reasons for using social media in this circumstance? 3. What is the prevalence of parents using social media post consultation for their child and what are their reasons for doing so?
Specifying levels of precision, such as standard errors, confidence intervals ("margin of error"), or statistical power	Standard error: $p= 0.05$ Confidence interval = 3.1
Deciding whether the survey will be repeated	Single time only
Establishing cost limits	Sum of HDR research fund and 2x UTS ECR funds = \$11331 AUD
Specifying whether the nature of the data to be collected - costs or other considerations - requires a certain data collection mode	Online data collection through a market research company (Quality Online Research - QOR)
<b>B. Sample design</b>	
Selecting (or planning to construct) a sampling frame	Email invitation to eligible respondents that are registered on QOR's panel.
Defining the strata, if any, to be employed	Australian Bureau of Statistics Australian Census 2016
Deciding whether the sample to be single stage, clustered or multistage design	Single stage
Determining sample size	1000 valid responses
<b>C. Questionnaire (data collection)</b>	
Translate dependent and independent variables into specific measurements	- Likert scales - Dichotomous questions - Single response questions - Multiple response questions
Use of validated instruments - adaptation of validated questions, repeat of validated questions	Baumann 2020 - selected questions adapted to the Australian context Frawley 2018 - selected questions repeated from 2018 study
Use of validated scales	Sosu 2013 - CTDS (used in full validated form) Ayre 2021 - PPSI (used in full validated form)
Development of new items	Questions that needed to be developed to align with the research questions and their objectives were created, iteratively adjusted and piloted
Ensure survey data collection methods are appropriate to the collection mode to be used	QOR took the final UTS Ethics approved instrument, and formatted it to their platform for optimal user experience (optimised for completion on mobile screens)
Draft and refine skip patterns	These were iteratively refined as the order of questions were changed during programming by QOR
Refine instrument (including question ordering effects) - Pre-pilot	A screener question was included at beginning of the survey to ensure that only eligible participants were able to proceed
<b>D. Operations planning</b>	
Research and select market research company - ensure compliance with relevant	SO20252, Market, Opinion and Social Research ADIA – Information & Data Security Compliance System Panel owned and managed in compliance with ISO20252

standards, codes and legislation to ensure data security and integrity	
Obtain UTS Human Research Ethics Committee approval for survey instrument	ETH21-6598
Consult with RMC to their capacity and capability to put survey into the field, mode and methods used by them	Online, mobile optimised, platform access for eligible participants. A small token incentive was offered per valid response (based on length of survey, time to complete ~ AUD 2.80/USD 1.80)
Consult with RMC to determine best timing for putting survey into the field	ASAP, pre-Christmas school holidays
Execute pilot	24 November 2011 – Valid responses: 122
Review pilot data for data quality	25 November 2021 - 28 November 2021
Execute full launch	29 November 2021
Close field work	14 December 2021 - Valid responses (including pilot): 1000
Review data	15 December 2021
Approve data and close fieldwork	16 December 2021
<b>E. Data analysis</b>	
Statistical analysis methods	Descriptive Statistics Chi-square tests of association Logistical regression
<b>F. Reporting guidelines</b>	
	STROBE (Appendix B) CROSS (Appendix C)

### 3.8 Qualitative study – Semi Semi-structured Interviews

Semi-structured interviews are a qualitative research method that allows for flexibility when collecting data (i.e. interviewing) from participants. Open-ended questions are the main method of obtaining data from participants, giving them the space to answer according to how they interpret the question, in the way they want to answer and how much information they want to give. The interviewer can also follow up on information given to explore a little further or seek clarification on the context (Braun & Clarke, 2013 p.4), all with the aim to gather “rich data (which reach) below the surface and allow the researcher to gain a deeper understanding of the topic of interest” (Braun & Clarke, 2013, p. 34). This also limits the amount of data that would potentially be lost due to not having context or understanding.

The benefits of semi-structured interviews are many. Besides allowing for flexibility for both the participant and the researcher, the participant (with a trained interviewer) can dictate the pace and boundaries of the interview, leading to a conversational flow of information and facilitating a deeper level of communication that might not occur if the participant was not comfortable or if the interviewer had not built rapport centred around the participant's needs (Braun & Clarke, 2013 p.10). All these factors lead to

the gathering of rich data around the participant's personal experiences and insights as the participant understands it (Braun & Clarke, 2013, p. 4; Rubin & Rubin, 2005, p. 35). This is vital when seeking meaning (Braun & Clarke, 2013, p. 20).

Using semi-structured interviews, however, is not always the best method of collecting qualitative data. The complexity of analysis requires a lot of time, resources and expertise, as well as many iterations, leading to long lead times (often years) between collection and publication (Braun & Clarke, 2013). This fact can make semi-structured interviews unsuitable for some research areas that move quickly or when findings are needed quickly to inform the next stage of research or funding.

As data is being collected by humans and given by humans, there is the potential for bias to be introduced into the data, mainly from the interviewer's involvement. However, with reflexive thematic analysis, bias is not bias – but rather embraces researcher subjectivity, acknowledging that thematic analysis is inherently subjective and that “meaning is not fixed within data” (Braun & Clarke, 2023). The flexibility that semi-structured interviews allow, by its very nature, doesn't lend itself to the positivist notion of standardisation (Braun & Clarke, 2013), which can lead to variations in the data collected, making analysis more complex.

Semi-structured interviews have their place in research, however, despite the challenges that they sometimes pose. They are an excellent way of exploring complex phenomena, especially where topics are complex and nuanced and driven by human experience (Braun & Clarke, 2013, p. 4). It allows for perspectives to be understood, gaining insight into experiences and perceptions of particular phenomena, especially phenomena that are sensitive or quite personal (Braun & Clarke, 2013, p. 80), that wouldn't be possible with quantitative methods or other qualitative methods such as focus groups. Semi-structured interviews are complementary to quantitative methods, and as with this thesis, when used in a mixed methods research design, semi-structured interviews allow for exploration of the depth of human experience, whereas quantitative methods allow for breadth and population experience (Johnson et al., 2007), combining to give a very comprehensive insight into the phenomena being explored.

### 3.8.1 Semi-structured interviews for this study

In this mixed methods research, for the qualitative arm, we used one-on-one semi-structured interviews to delve into the use of social media by Australian parents to find health information concerning their children, adopting a phenomenological standpoint. Phenomenology enabled an exploration of the lived encounters and subjective viewpoints of parents who used social media for their children's health-related information. The objective was to understand parents' individual journeys of using social media to access health information for their children and to uncover any common threads among the interviewed parents. Approval for this study was obtained from the Human Research Ethics Committee (HREC) at the University of Technology Sydney (ETH21-5799).

#### 3.8.1.1 *Research questions*

RQ1: How do parents use social media for health information for their child?

RQ2: Which aspects of using social media for health information do parents find valuable?

RQ3: Which aspects of using social media for health information do parents find challenging?

RQ4: How do parents determine what information to trust and act on from social media?

#### 3.8.1.2 *Participants and recruitment procedure*

Purposive sampling was utilised to recruit Australian parents who use social media to find health information regarding their children. Eligible participants were required to have at least one child under 18 years old and seek health advice via social media platforms. Exclusion criteria included individuals unable to participate via Zoom/Skype or unwilling to consent to interview recordings (as a disability accommodation for the interviewer). Recruitment strategies included the distribution of posters and targeted social media advertisements (approximately AUD300). The researcher disseminated recruitment posters to 86 Facebook groups, focusing on geographical (e.g. North Sydney Living) or child/parenting-oriented communities (e.g. Inner West Mums) across

Australian states and territories. To ensure voluntary participation, a distinct and separate consent process was outlined by the UTS Human Research Ethics Committee, with the intention to eliminate any actual or perceived coercion or obligation. Prospective participants accessed a survey page on Qualtrics XM (Qualtrics XM, 2021) through a QR link on recruitment posters, where they received a Participant Information Sheet (PIS) for comprehensive disclosure, allowing them to make an informed decision about participation. Those willing to participate provided their contact information to schedule an interview with the researcher via Zoom (Zoom, 2021). A total of 19 eligible parents were interviewed for this research.

### *3.8.1.3 Data analysis*

Reflective Thematic Analysis (Reflexive TA) (Braun & Clarke, 2021) served as the analytical approach for this study, offering a structured yet adaptable methodology. Reflexive TA necessitates the researcher's subjective engagement, awareness, and critical inquiry into the data, facilitating dynamic interpretation and comprehension throughout the analysis process (Byrne, 2022).

The doctoral student and collaborators adhered to the phases of Reflexive TA;

- (1) data familiarisation,
- (2) data coding,
- (3) initial theme generation,
- (4) theme development and review,
- (5) theme refining, defining, and naming,
- (6) writing up.

Inductive analysis allowed the data to guide code and theme development. The analysis aimed to capture and explore participants' comprehension of and perspectives on their experiences, with a focus on underlying meanings. A relativist/constructionist theoretical framework was adopted to deconstruct participants' experiences and understand the phenomenon within the dataset (Braun & Clarke, 2021). The study was reported using the Standard for Reporting Qualitative Research (SRQR) (O'Brien, 2014) (Appendix E).

An overview of the qualitative study is provided below (Table 3.3)

Table 3.3 Overview of the study – qualitative study

Interview design element/ consideration (adapted from Creswell 2013, Chapter 7)	How this was done in this qualitative research (refer to Chapter 5 for full description of methods in publication)
<b>A. Research Design</b>	
Data collection activity	Phenomenology
Decide on the research questions	<ol style="list-style-type: none"> <li>4. How do parents use social media for health information for their child?</li> <li>5. What aspects of using social media for health information do parents find valuable and challenging?</li> <li>6. How do parents determine what information to trust and act on from social media?</li> </ol>
Nature of data to be collected	Zoom one-on-one interviews with eligible parents
<b>B. Sample Design – on paragraph</b>	
Identify interviewees	Parents of children that have used social media for health information for their child aged 0-18
Sample size	19 Interviews (consistent with Phenomenology - Polkingholme 1989, Braun and Clarke 2013)
Determine type of interview	Semi-structured interview - single interview
<b>C. Interview (data collection) one paragraph</b>	
Design and use interview protocol	Interview guide: semi-structured interview guide (Appendix D) Distress protocol Participant Interview Sheet (PIS)
Pilot questions	Three colleagues were asked to review and comment on the questions before they were submitted to Ethics for final review and approval for use
Determine place for interview	Zoom at a mutually agreed time
<b>D. Operation planning</b>	
Recruitment	Facebook ads, Facebook groups, Instagram poster, Twitter poster. Snowballing
Recruitment period	November 2021 to March 2022
Use adequate recording procedures	Zoom interview, recorded (video and audio)
Consent from interviewee	Obtained verbally before commencement of the interview (by Ethics approved script, with acknowledgement of this having been done off camera at the commencement of the interview by participant)
Interview procedures	Interview Guide (HREC approved)
Follow up	Email participant transcript for their final approval to use all or part of the interview Enrolment to the dissemination plan for the research
Data collected	Interview recording (identifiable)- video Interview recording (deidentified)- audio Transcript (deidentified) - text
Qualitative data analysis method/s	Reflexive Thematic Analysis with NVivo12 software
Reporting Guideline	Standards for Reporting Qualitative Research (SRQR) (Appendix E)



### 3.9 Conclusion

This chapter has explored this thesis's methodology, including the philosophical, epistemological, and ontological foundations. It has also discussed the rationale and considerations for using mixed methods for this research. The conceptual frameworks for this research were also discussed, including phenomenology and Bandura's Triadic Reciprocal Determinism, to explain how this research was framed in order to understand the phenomenon being investigated – why Australian parents use social media for health information.

The methods used were described in this chapter, with each arm of the study's research design explored in detail, as well as individual summary tables for each arm of the study.

The next chapter is the first of three results chapters in this thesis. The first results chapter presents a quantitative analysis of a representative study across 1000 Australian parents exploring their motivations and sentiments when using social media for health information generally, but also before and after seeking professional health care.

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## Chapter 4: Quantitative Study 1

### 4.1 Introduction

This chapter presents the results of the Quantitative Phase 2 of this research project in the form of a peer-reviewed paper published in the JMIR Pediatrics and Parenting Journal in 2023 (see the formal citation below). These results derive from the scoping review finding that parents use social media prior to and after seeking health information from healthcare professionals and that most information obtained is shared with others by parents with no medical or health training. The motivations for this are under-researched, so this research paper presents the results of an attempt to quantify this phenomenon for the Australian population.

The statistical analysis employed for this quantitative phase used a representative cross-sectional survey tool to obtain the data presented. This comprised a descriptive analysis for sociodemographic data,  $\chi^2$  tests of association to establish significance, and logistical regression analysis to determine predictors.

New findings centred around Australian parents' reasons for using social media after seeing health care professionals. These reasons included wanting to see examples of other parents' lived experiences, seeking out further information not provided in the consultation, or trying to clarify information obtained.

The enclosed paper addresses the first and second objective of this research:

1. To describe the prevalence of Australian parents who use social media for health information for their children.
2. To determine the characteristics, determinants and motivations of Australian parents that use social media for health information for their children.

### 4.2 Publication Details

This paper was accepted for publication in JMIR Pediatrics and Parenting (2023 IF 3.7) in August 2023 and published online in October 2023.

Frey E, Bonfiglioli C, Frawley J. (2023). Parents' use of social media for health information before and after a consultation with health care professionals: Australian cross-sectional study. *JMIR Pediatrics and Parenting*; 6:e48012. URL: <https://pediatrics.jmir.org/2023/1/e48012>. doi: 10.2196/48012

## 4.3 Parents' Use of Social Media for Health Information Before and After Consultation with Health Care Professionals: Australian Cross-Sectional Study

[Original Paper](#)

### Parents' Use of Social Media for Health Information Before and After a Consultation With Health Care Professionals: Australian Cross-Sectional Study

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#### Abstract

**Background:** Social media is a crucial source of health information for many parents due to its integration into modern life, raising critical concerns for public health. Parents use various social media platforms to find health information for their children, with most information created and shared by parents with no medical or health training. The extent to which parents seek health information from social media before and after a consultation and their motivations for doing so remain underresearched.

**Objective:** This study aimed to investigate Australian parents' use of social media for health information for their children, aged between 6 months and 5 years, before and after consulting with health care professionals.

**Methods:** A representative cross-sectional survey of 1000 Australian parents with children aged 6 months to 5 years was conducted between November and December 2021. Data were cleaned and analyzed using IBM SPSS software. The primary outcomes were (1) parental motivation and prevalence of social media use for health information and (2) parental motivation for using social media before and after a consultation with their child's health care professional.

**Results:** Of the 1000 parents surveyed, 82.2% (n=822) reported using social media for health information for their child. Parents were more likely to consult social media before and after a health consultation if they were aged 30-39 or ≥50 years and born in Australia. Parents with higher levels of education were less likely to consult social media. Parents were motivated to seek health information before a consultation for a variety of reasons, including exchanging opinions and experiences (639/767, 83.3%), having information that is available 24/7 (622/767, 81.1%), receiving emotional support (599/767, 78.1%), having previous positive experiences (597/767, 77.8%), and having friends and family that use social media for health information (577/767, 75.2%). Parents sought information after a consultation to connect with parents with similar experiences (546/794, 68.8%), seek a second opinion (505/794, 63.6%), fact-check information provided by their health care professional (483/794, 60.8%), and look for other treatment options (353/794, 44.5%).

**Conclusion:** Using social media for child health information is part of the modern parenting experience. It can be challenging to discern the quality of health information on social media, leaving parents open to incorrect information and misinformation. Although access to immediate social support is a welcomed feature of social media, receiving incorrect health information can have unwanted consequences for the child, family, health provider, and wider community. The upskilling of parental health literacy to navigate the unique health literacy challenges that social media brings, alongside the creation and delivery of accessible, evidence-based information in varying formats, is urgently required. The provision of this information is the responsibility of every level of the health system, not just the treating health care professional.

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**Keywords:** social media; information seeking behavior; parenting; child; infant; health literacy; patient education; digital platform; information; health information; public health

## Introduction

Social media platforms such as Facebook, Instagram, Twitter, Pinterest, and YouTube are key resources for parents seeking health information for their children [1-4]. The convenience and opportunity to meet like-minded parents has made social media central to modern parenting. In contrast to traditional health information accessed via books, internet web pages, or health care professionals, social media gives access to immediate health information from like-minded people, which is more likely to be ideologically aligned than evidence based. This democratization of health information risks downstream impacts including abstinence from formal health care [4], delay in seeking necessary health care [5], and the choice of non-evidence-based treatments [6], all of which impact health outcomes for children.

More broadly, the use of social media by parents has implications for health care professionals and public health. Although traditionally, health care professionals were one of the limited sources for health information that parents could find, health information can now be sourced almost instantaneously. This has direct impacts on how health care professionals provide care to their pediatric patients, with parents being able to actively seek out alternative information that may contradict or challenge the evidence-based information and treatment options that are being offered to them and their child during consultations [7,8]. Poor quality information from non-evidence-based sources has impacts on the community more broadly, with misinformation spread in the community setting by way of stories based on lived experience or rumor being exchanged between parents. Research has shown that misinformation can impact parents' health decisions [9], for example, decisions about infectious disease and childhood immunization. Finally, when delayed evidence-based health care is eventually sought by parents, it is the health system that needs to provide it. This may result in more intense and resource-heavy care for the child [10].

Parents need to have a more diverse and honed set of health literacy skills when using social media for health information than previously required. This is due to the available health information being authored, compiled, or shared by parents that have little to no health expertise, making it almost certain to have a subjective bias to some degree. However, it is also because of this very fact that parents are seeking health information on social media—to gain insights from the lived experience of other parents further ahead on the same health journey that they have found themselves on. The skills needed to navigate social media health information sources include being able to discern quality evidence-based information from that of opinion [1] and politically or emotionally driven information [6]; tracing information to its source to determine context and relevance [11]; having the numeracy skills to be able to discern relative and absolute risk [9]; as well as being able to manage the sheer

amount of information that is available [12], all of which is vying for the parent's attention. In addition, parents need to have sophisticated social skills to be able to access some forms of health information, especially that of lived experience from other parents, where potentially complex interpersonal and group dynamics [13] can complicate access.

A variety of intrinsic and extrinsic factors have been found to motivate parents' use of social media for health information. Intrinsic motivations include an increased sense of empowerment [6,14], self-efficacy, and self-determination and feeling more educated about the condition of concern [15,16]. Extrinsic motivators include being able to socialize [17] with like-minded people [18] to exchange support and advice [14,17,19], being offered reassurance and validation for health decisions [20], normalizing the challenges experienced [21], and having a sense of safety and privacy [18].

Three studies to date have provided evidence that parents use social media for health information before and after a diagnosis because they are medically underserved [14], want to use alternative health care [6], lack information that aligns with their health goals for their child [18], or lack appropriate information from health care professionals [18]. These studies focus on niche groups (those who are vaccine hesitant, infants with severe combined immunodeficiency, and mothers who exclusively express and bottle-feed) [4,14,18]. Social media's utility has been demonstrated within these niche groups. However, considering social media's ubiquity and fast pace of adoption and integration into people's lives on a population level, we sought to understand how prevalent parents' use of social media for health information before and after a health consultation is, alongside the reasons that parents use social media for health information. This representative study investigated the use of social media for health information among Australian parents, before and after consulting with health care professionals.

## Methods

### Study Design

A national quantitative cross-sectional survey was conducted between November and December 2021 among Australian parents of children aged 6 months to 5 years. For this study, "parent" was defined as anyone that was a biological parent, adoptive parent, or court-appointed guardian or caregiver of a child aged between 6 months and 5 years.

### Variables

A 47-item survey developed from previously validated tools combined multiple-choice questions with optional open-text fields and Likert scales [22,23]. The first

section explored parents' use of social media, the information sought, and motivations for using social media for child health information. The next section asked parents about their motivations for using social media before consulting with a health care professional. The final section asked parents their motivations for using social media for health information after consulting with a health care professional. Demographic data were collected.

A web-based research company (Quality Online Research [QOR]) was engaged to recruit parents from their web-based panel of preregistered participants and to administer the survey. Parents were recruited by way of a single-use email link, preventing multiple responses from a single participant. Eligibility criteria included being an Australian citizen or permanent resident who is caring for a child aged 6 months to 5 years. The company identified the participants by the demographic information that the participants provided when they joined the panel in preparation for survey opportunities. For our study, this was guided by our inclusion criteria. Exclusion criteria were limited command of the English language and not having an active social media account.

Due to the large and unknown population of parents of children aged 6 months to 5 years, a sample size of 1000 was chosen to give a CI of 3.1. Stratification parameters of the Australian 2016 census [24] ensured that the sample was representative of Australian states and territories and gender demographics. Parents were offered a small incentive (about Aus \$2.80 [US \$1.80]) to participate. The survey was refined with 2 rounds of corrections during the prepilot phase to ensure skip steps and question formatting were done correctly. The survey was pilot-tested among 122 parents, with responses checked by researchers for quality before being formally launched in the field. Fieldwork took 16 days (November to December 2021) to gather a total of 1000 eligible completed surveys (including the pilot test) from parents. The survey was kept at arm's length from the researchers and was administered by QOR, with the data being cleaned and anonymized by QOR before being transferred to the researchers for analysis. The cleaned data were checked for quality control by researchers before commencing statistical analysis.

### **Ethical Considerations**

Participants were presented with a participant information sheet (PIS) as the first screen after opening the email link from QOR. This PIS informed participants about the project, why they have been invited (inclusion criteria), what their participation will involve, and the risks and inconvenience they can expect. They were also made aware that their participation was entirely voluntary and that there would be no penalty for their withdrawal at any point during the survey. Participants indicated their consent by commencing the survey after reading the PIS. As the data were being collected by a third-party research company, the researchers were not, at any point, exposed to any identifying information. Participants

were given direct contact information for both the Ethics Secretariat and the lead investigator, if they required further information or follow-up. There was a consent form that outlined the main points highlighted in the PIS, which participants were able to click out of if they wished to discontinue or click forward to continue with the survey. Discontinuing their participation in the survey (returning an incomplete survey) was counted as a withdrawal, with the data being excluded from the final analysis. Ethics approval was obtained from the Human Research Ethics Committee at the University of Technology Sydney (UTS HREC ETH21-6598). This report is guided by the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) statement [25] for cross-sectional studies with supplementary guidance from the Consensus-Based Checklist for Reporting of Survey Studies [26].

### **Analysis**

Data were imported to IBM SPSS Statistics for Mac (version 28; IBM Corp) [27] for analysis. Descriptive statistics were calculated for sociodemographic data and parental use of social media.  $\chi^2$  tests of association were conducted to determine which aspects of parent motivation were statistically significant. Logistic regression was used to determine the significant predictors of social media use for health information before or after a consultation with a health care professional. Covariates with  $P < .25$  were entered into the model, as well as Socio-Economic Indexes for Areas (The Index of Relative Socio-economic Advantage and Disadvantage) [28] codes corresponding to postcodes. Statistical significance was set at  $P < .05$  to produce the most parsimonious model. There were some missing data (26/1026, 2.5%), possibly either due to participant error when entering their postcode or circumventing the requirement to answer before proceeding to the next question.

### **Results**

Of the 1563 parents who opened the survey link in QOR's email invitation, 1026 (65.6%) completed the survey. In all, 26 surveys were deemed ineligible for analysis upon further data cleaning, leaving 1000 surveys for analysis, indicating a 64% (1000/1563) completion rate. Of the 1000 Australian parents surveyed, 57.5% ( $n=575$ ) identified as female, 41.3% ( $n=413$ ) identified as male, 0.8% ( $n=8$ ) identified as nonbinary, and 0.4% ( $n=4$ ) preferred not to say. Only 9.4% ( $n=94$ ) of parents were not born in Australia (Table 1). Australian-born participants were found to be statistically more likely to use social media for their children's health than non-Australian-born participants ( $P=.009$ ). Variations by gender ( $P=.59$ ); marriage status ( $P=.64$ ); location by state ( $P=.71$ ); language spoken at home ( $P=.69$ ); and metro, rural, or remote location ( $P=.50$ ) were not statistically significant. Covariates with  $P < .25$  were imported into a logistic regression for further analysis.

**Table 1.** Participant characteristics.

Characteristics	Total (n=1000), n (%)	Use social media (n=822), n (%) <sup>a</sup>	Do not use social media (n=178), n (%) <sup>a</sup>	P value
<b>Gender</b>				.59
Male	413 (41.3)	340 (82.3)	73 (17.7)	
Female	575 (57.5)	471 (81.9)	104 (18.1)	
Nonbinary	8 (0.8)	8 (100)	0 (0)	
Prefer not to say	4 (0.4)	3 (75)	1 (25)	
<b>Age group (years)</b>				.12
18-29	308 (30.8)	255 (82.8)	53 (17.2)	
30-39	412 (41.2)	343 (83.3)	69 (16.7)	
40-49	235 (23.5)	193 (82.1)	42 (17.9)	
≥50	45 (4.5)	31 (68.9)	14 (31.1)	
<b>Location (by state or territory)</b>				.71
New South Wales	322 (32.2)	268 (83.2)	54 (16.8)	
Australian Capital Territory	13 (1.3)	10 (76.9)	3 (23.1)	
Queensland	205 (20.5)	174 (84.9)	31 (15.1)	
Victoria	269 (26.9)	214 (79.6)	55 (20.4)	
South Australia	75 (7.5)	59 (78.7)	16 (21.3)	
Tasmania	29 (2.9)	25 (86.2)	4 (13.8)	
Northern Territory	4 (0.4)	4 (100)	0 (0)	
Western Australia	83 (8.3)	68 (81.9)	15 (18.1)	
<b>Education</b>				.05
High school	273 (27.3)	219 (80.2)	54 (19.8)	
Trade qualification <sup>b</sup>	193 (19.3)	150 (77.7)	43 (22.3)	
University qualification	534 (53.4)	453 (84.8)	81 (15.2)	
<b>Marital status</b>				.64
Never married	207 (20.7)	169 (81.6)	38 (18.4)	
Married or de facto marriage	754 (75.4)	623 (82.6)	131 (17.4)	
Separated, divorced, or widowed	39 (3.9)	30 (76.9)	9 (23.1)	
<b>Country of birth</b>				.009
Australia	906 (90.6)	754 (83.2)	152 (16.8)	
Outside of Australia	94 (9.4)	68 (72.3)	26 (27.7)	
<b>Language spoken at home</b>				.69
English	955 (95.5)	786 (82.3)	169 (17.7)	
Other	45 (4.5)	36 (80)	9 (20)	
<b>SEIFA<sup>c</sup> (n=974 valid responses)</b>				.18
Q1 (highest)	213 (21.3)	179 (84)	34 (16)	
Q2	218 (21.8)	178 (81.7)	40 (18.3)	
Q3	217 (21.7)	168 (77.4)	49 (22.6)	
Q4 (lowest)	326 (32.6)	275 (84.4)	51 (15.6)	
First child	769 (76.9)	623 (81)	146 (19)	.07
Metro	601 (60.1)	498 (82.9)	103 (17.1)	.50

<sup>a</sup>Percentages reflect the proportion of each subgroup (ie, the denominator is the n value in the Total column).

<sup>b</sup>Apprenticeship or other training to become a tradesperson.

<sup>c</sup>SEIFA: Socio-Economic Indexes for Areas (The Index of Relative Socio-economic Advantage and Disadvantage) [28].

A majority (822/1000, 82.2%) of parents used social media for information about their child's general health and well-being. Parents were asked about their general motivations for using social media for health information (Table 2), before and after consulting a health care professional. Health care consultations were not defined beyond "visited the health care professional of

your choice" to include any clinic or hospital visit. Parents' use of social media for health information before a consultation was motivated by the ability to exchange opinions and experiences with other parents (639/767, 83.3%;  $P=.002$ ), the information being available 24/7 (622/767, 81.1%;  $P<.001$ ), receiving emotional support from other parents (599/767, 78.1%;  $P=.002$ ),

positive previous experiences using social media for health information (597/767, 77.8%;  $P<.001$ ), having friends and family use social media for health information (577/767, 75.2%;  $P<.001$ ), and the information being up to date (518/767, 67.5%;  $P<.001$ ). Parents' motivations for using social media after a consultation were similar, with the addition of anonymity while seeking health information (543/749, 72.5%;  $P=.009$ ).

**Table 2.** Australian parents' sentiments about using social media for health information.

Sentiment	Total (n=822), n (%) <sup>a</sup>	Use social media before an HCP <sup>b</sup> visit, n (%) <sup>a</sup>		P value	Use social media after an HCP visit, n (%) <sup>a</sup>		P value
		Yes (n=767)	No (n=55)		Yes (n=749)	No (n=73)	
<b>The information is available 24/7</b>				<.001			.008
Agree	652 (79.3)	622 (81.1)	30 (54.5)		598 (79.8)	54 (74)	
Neutral	113 (13.7)	96 (12.5)	17 (30.9)		98 (13.1)	15 (20.5)	
Disagree	57 (6.9)	49 (6.4)	8 (14.5)		53 (7.1)	4 (5.5)	
<b>The information is up to date</b>				<.001			<.001
Agree	540 (65.7)	518 (67.5)	22 (40)		512 (68.4)	28 (38.4)	
Neutral	213 (25.9)	189 (24.6)	24 (43.6)		174 (23.2)	39 (53.4)	
Disagree	69 (8.4)	60 (7.8)	9 (16.4)		63 (8.4)	6 (8.2)	
<b>I can retain my anonymity (people don't know who I am)</b>				.10			.009
Agree	583 (70.9)	551 (71.8)	32 (58.2)		543 (72.5)	40 (54.8)	
Neutral	168 (20.4)	150 (19.6)	18 (32.7)		142 (19)	26 (35.6)	
Disagree	71 (8.6)	66 (8.6)	5 (9.1)		64 (8.5)	7 (9.6)	
<b>I have had good experiences with it</b>				<.001			<.001
Agree	624 (75.9)	597 (77.8)	27 (49.1)		583 (77.8)	41 (56.2)	
Neutral	168 (20.4)	142 (18.5)	26 (47.3)		136 (18.2)	32 (43.8)	
Disagree	30 (3.6)	28 (3.7)	2 (3.6)		30 (4)	0 (0)	
<b>My friends and family use them as well</b>				<.001			<.001
Agree	603 (73.4)	577 (75.2)	26 (47.3)		565 (75.4)	38 (52.1)	
Neutral	160 (19.5)	136 (17.7)	24 (43.6)		135 (18)	25 (34.2)	
Disagree	59 (7.2)	54 (7)	5 (9.1)		49 (6.5)	10 (13.7)	
<b>It's a place where I can exchange opinions and experiences with other parents</b>				.002			<.001
Agree	678 (82.5)	639 (83.3)	39 (70.9)		624 (83.3)	54 (74)	
Neutral	119 (14.5)	106 (13.8)	13 (23.6)		105 (14)	14 (19.2)	
Disagree	25 (3)	22 (2.9)	3 (5.5)		20 (2.7)	5 (6.8)	
<b>To receive emotional support from other parents</b>				.002			.007
Agree	633 (77)	599 (78.1)	34 (61.8)		584 (78)	49 (67.1)	
Neutral	142 (17.3)	122 (15.9)	20 (36.4)		122 (16.3)	20 (27.4)	
Disagree	47 (5.7)	46 (6)	1 (1.8)		43 (5.7)	4 (5.5)	

<sup>a</sup>Some percentages may not sum to 100% due to rounding.

<sup>b</sup>HCP: health care professional.

When asked which statements were true of their use of social media for health information, parents' responses varied (Table 3). A total of 60% (503/838) of parents sought general information about a condition of concern for their child on social media. Parents used social media to determine if medical attention was required (363/838, 43.3%) and seek information about

alternative treatments such as natural remedies (350/838, 41.8%) and other medical treatments (293/838, 35%) for the condition of concern. When seeking general health information, parents were the least likely to use social media for information about self-management strategies (292/838, 34.8%).

**Table 3.** Parental motivations for using social media for children's health information.

Motivations for using social media	Yes <sup>a</sup> , n (%)
<b>Children's health information in general (n=838)</b>	
To seek general information about the health problem or illness	503 (60)
To determine if medical attention was required	363 (43.3)

Motivations for using social media	Yes <sup>a</sup> , n (%)
To seek information about alternative treatments for the health problem or illness	350 (41.8)
To seek information about possible medical treatments for the health problem or illness	293 (35)
To seek information about self-management strategies	292 (34.8)
<b>Health information before a health care professional visit (n=823)</b>	
To seek general information about the health problem or illness	510 (62)
To determine if medical attention was required	425 (51.6)
To seek information about alternative treatments for the health problem or illness	351 (42.6)
To seek information about possible medical treatments for the health problem or illness	326 (39.6)
To seek information about medications	325 (39.5)
<b>Health information after a health care professional visit (n=794)</b>	
To find examples of lived experience	546 (68.8)
I wanted a second opinion	505 (63.6)
To check the information I received at the doctor's office	483 (60.8)
To seek further information about the health problem or illness	453 (57.1)
To determine if further medical attention was required	373 (47)
I did not receive enough information at the doctor's office or clinic	364 (45.8)
The information from the doctor's office was unclear	357 (45)
To seek information about alternative treatments for the health problem or illness	353 (44.5)
To seek information about possible medical treatments for the health problem or illness	314 (39.5)
To seek information about medications	291 (36.6)

<sup>a</sup>Parents were asked to check all that applied.

When parents were asked about seeking information on social media before a consultation, most (510/823, 62%) looked for information about the health condition. About half (425/823, 51.6%) sought to determine if medical attention was required. Alternative treatments (351/823, 42.6%) were sought also, with 39.5% (326/823) of parents seeking information about (other) possible medical treatments.

When parents were asked about their motivations for using social media for health information after visiting a health care professional, 68.8% (546/794) stated they did so because they wanted to find examples of lived experience. Parents also wanted a second opinion (505/794, 63.6%), to check the information provided during the consultation (483/794, 60.8%), or to seek further information about the health condition (453/794, 57.1%). Just under half of all parents who used social media after a consultation did so to determine if further medical attention was required (373/794, 47%), having felt that they did not receive enough information from their health care professional (364/794, 45.8%), or that the information they were given was unclear (357/794, 45%). Other reasons included wanting to seek alternative treatments (353/794, 44.5%), information about possible medical treatments for the condition (314/794, 39.5%), or information about medications (291/794, 36.6%).

The results of the logistic regression conducted (Table 4) show that Australian-born parents were more likely to use social media for health information for their children both before (odds ratio [OR] 2.545, 95% CI 1.521-4.259) and after a health consultation (OR 2.045, 95% CI 1.228-3.407) than those born outside of Australia. Parents aged 30-39 years were the most likely to use social media before (OR 3.212, 95% CI 1.475-6.996) and after a consultation (OR 3.799, 95% CI 1.821-7.926) when compared to the reference group of parents aged 18-29 years. Parents aged ≥50 years were also more likely to use social media before (OR 2.324, 95% CI 1.066-5.068) and after a consultation (OR 3.428, 95% CI 1.625-7.233) than parents aged 18-29 years.

Education was a significant predictor for social media use among parents before and after a consultation. Parents with university (OR 0.513, 95% CI 0.332-0.794) or trade qualifications (OR 0.535, 95% CI 0.352-0.814) were less likely to consult social media before a consultation than parents with high school qualifications. Parents with a university (OR 0.515, 95% CI 0.319-0.719) or trade qualification (OR 0.631, 95% CI 0.395-0.882) were also less likely to use social media for health information after a health consultation.

**Table 4.** Predictors for parental use of social media before and after a consultation with a health care professional.

Predictor	Use social media before consultation		Use social media after consultation	
	OR <sup>a</sup> (95% CI)	P value	OR (95% CI)	P value
<b>SEIFA<sup>b,c</sup></b>				
Q1 (highest)	Reference		Reference	
Q2	1.666 (1.027-2.700)	.04	1.270 (0.796-2.027)	.32



Predictor	Use social media before consultation		Use social media after consultation	
	OR <sup>a</sup> (95% CI)	P value	OR (95% CI)	P value
Q3	0.795 (0.519-1.335)	.45	0.685 (0.429-1.093)	.11
Q4 (lowest)	1.252 (0.776-2.086)	.34	0.885 (0.551-1.423)	.62
<b>Age group (years)</b>				
18-29	Reference		Reference	
30-39	3.212 (1.475-6.996)	.003	3.799 (1.821-7.926)	<.001
40-49	1.918 (0.917-4.010)	.08	1.818 (0.912-3.626)	.09
≥50	2.324 (1.066-5.068)	.03	3.428 (1.625-7.233)	<.001
<b>Country of birth</b>				
Outside of Australia	Reference		Reference	
Australia	2.545 (1.521-4.259)	<.001	2.045 (1.228-3.407)	.006
<b>Education</b>				
High school	Reference		Reference	
Trade qualification	0.535 (0.352-0.814)	.003	0.631 (0.395-0.882)	.01
University qualification	0.513 (0.332-0.794)	.003	0.515 (0.319-0.719)	<.001

<sup>a</sup>OR: odds ratio.

<sup>b</sup>SEIFA: Socio-Economic Indexes for Areas (The Index of Relative Socio-economic Advantage and Disadvantage) [28].

<sup>c</sup>974 responses included.

## Discussion

### Principal Findings

The Australian parents most likely to use social media for health information before and after a consultation were aged 30-39 years (Generation Y or millennials) and born in Australia. Reasons for this could include that because Generation Y or millennials, as digital natives, have their parenting experience colored by their everyday use of social media, digital health information and traditional health information are seamlessly intertwined [29]. Parents with university education were found to be the least likely to use social media for health information before or after a health consultation, which is consistent with other studies [2]. This may reflect literacy or health literacy confidence. Parents who have higher levels of education may be more confident to seek health information, resulting in being able to ask pertinent questions and better understand the health information received during a health consultation. This allows the parent to leave the health consultation feeling satisfied with the information they have received [30].

Previous studies have sought to understand why parents use social media for general health information. Reasons have included social media's information immediacy [20]; timely access despite geographical [21] or logistical [15] barriers; detailed, customized, and relevant information [20]; and perceived trustworthiness [31]. Parents view social media as being unbiased [20], aligning with their personal perspectives [21] and values [32], and providing insights to lived experience not available elsewhere [19,21].

Although parents' use of social media before a health consultation is often to seek information about a health issue or to determine if treatment is needed, some of the reasons why parents may use social media for health information

after a consultation raise questions about communication and health literacy. Almost half of all Australian adults read at a low level [33] and 60% have low levels of health literacy [34], with both of these factors potentially creating barriers to parents' understanding of traditional health information. Social media health information is multimodal, combining personal stories, conversational text, videos, infographics [35], subtitles, and other design features that make it more inclusive for those with varying literacy levels [36]. The interactive and conversational nature of social media makes information more accessible, making it a preferable source for some parents [32]. Our nationally representative study shows that this is not only the experience of parents who are part of specific niche groups, as shown in the extant literature [14,16,18,19], but is true of the wider parenting experience.

Health information goes beyond the evidence-based information provided by health care professionals in consultations [2]. Parents seek emotional support [2] on social media and insights into how the health journey will impact their child, themselves, and their wider orbit. This information (which is often practical [32]) from other parents with lived experience is highly valued and sought after, allowing parents to feel more empowered and socially supported [37], thus increasing self-efficacy [16,38]. The democratized sharing of stories of lived experience is a unique feature of social media, which is also a strong motivator for parents who use social media for health information. Stories of lived experience allow parents to see what might lie ahead for their health journey, providing reassurance while also allowing them to allay uncertainties. It also allows parents to get health information beyond the clinical data, with practical tips and help to navigate the health system. Although these are only a few examples of information sought by parents based on lived experience, the power of stories for health communication has been long established. A scoping review by Dudley

et al [39] found that narratives are appealing to audiences, stimulate emotions, make it easier to understand health and science information, improve the memory of information, and capture attention through suspense. Stories also “enable people to make sense of themselves, others, relationships, responsibilities, life changing circumstances, uncertainties, their social world, and possible futures” [40], all of which are heightened at emotionally vulnerable times such as when a child is unwell. Stories also make the parent more open to the messaging held within a story, whether that be evidence based or not, which is where social media starts to reveal its complexity as a health information source. Although stories on social media make health information easier for parents to understand, the use of social media for health information brings with it health literacy challenges unique to social media. For example, when using social media to seek health information, parents need to be able to distinguish evidence-based health information from low-quality information, a lot of which is delivered by stories, within conversations, or as part of a social information exchange. This requires a parent to be able to navigate the dynamic social context they are currently in; use high-level health literacy skills; and if required, research context and the original source of information, all simultaneously in real time. Rarely, if at all, has this combination of skills been required previously of parents when seeking health information, let alone at the level of sophistication that is often required by social media. As a result, the lack of the unique health literacy skills as required by social media often results in parents being ill-equipped to navigate the health information available on social media.

For health care professionals, it may be of value to consider how to integrate better provision of accessible evidence-based health information to parents [41] into their practice. By accepting the use of social media for health information as the “new normal,” clinicians can also facilitate frank conversations with parents [42] about reliable web-based information sources and offer high-quality information in more accessible forms, such as referring patients to videos formatted for viewing on mobile phones and social media content known to be evidence based or facilitating live question and answer sessions on Instagram or TikTok.

Finally, the impacts of using social media for health information will inevitably seep into other aspects of the health system, including public health. This can perhaps be seen most clearly with preventable childhood infectious diseases. With parents independently accessing non-evidence-based, emotively laden, and politically motivated health information [41], primary prevention gains may be lost (whether it be lowered rates of disease or the elimination of disease) with an increase in outbreaks of diseases, as seen overseas [43] such as the Disneyland measles outbreak in 2014 [8]. This led to public health units needing to invest in health promotion resources to highlight the importance of vaccination and fund programs to boost vaccination coverage to sustain herd immunity.

The scarcity of accessible evidence-based health information that meets parents’ information needs leaves parents

vulnerable to finding low-quality health information when they turn to social media. Inclusive, accessible, and evidence-based health information urgently needs to be more readily available at all levels, from public health units down to in-consultation resources for health care professionals to guide conversations, as well as postconsultation resources for parents to take home. This will allow parents to consider evidence-based information in their own time, improve patient education, and reduce the reliance on non-evidence-based health information found on social media [44].

### Limitations

Inherent with any cross-sectional study design, responder bias is a confounding factor. Although measures were taken to limit the impact of responder bias, including having very broad inclusion criteria not related to the survey questions, as well as the stratification of data to the Australian Bureau of Statistics 2016 census data, the fact that the participants were from the research company’s preselected panel is a limitation.

Second, this survey required proficiency in English. Although the participants were stratified to be representative of the broader Australian population, not providing the survey in multiple languages limits representativeness in a multicultural society.

Third, the inclusion criteria stipulated that only parents with a social media account were to be included in this study. To access this survey, parents had to be able to access an internet connection; as such, we did not ask about their access to the internet as infrastructure was outside the scope of this study. This, however, did limit the study to only include those that have access to both the internet and social media.

Lastly, although cross-sectional studies cannot demonstrate causation, this study establishes a baseline for further research in this emerging area, which has substantial implications for clinical practice.

### Conclusion

With many Australian adults having low levels of health literacy, and almost half of all parents who used social media after a consultation reporting that the information from their health care professional was unclear, how evidence-based health information is delivered needs to be reconsidered to meet parents at their health literacy level. This could include resources that take a similar form to those found on social media that parents are already engaging with, such as those that are simplified, graphic, or video based. Public health units and, more broadly, the health system can support clinicians with their education of parents by providing inclusive health promotion communications and resources that are reliable and evidence based and meet parents at their health literacy level. Parents of patients could then be directed to quality resources, leading to health decisions that are informed and supported by evidence-based health information.

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### Data Availability

The data sets generated and/or analyzed during this study are not publicly available, as there are further reports to be published by the authors. The data will be available from the corresponding author after all reports from the data set have been completed and published.

### Conflicts of Interest

None declared.

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#### Abbreviations

**OR:** odds ratio

**PIS:** participant information sheet

**QOR:** Quality Online Research

**STROBE:** Strengthening the Reporting of Observational Studies in Epidemiology

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#### 4.4 Chapter Conclusion

This chapter presented a representative cross-sectional study investigating Australian parents' use of social media for health information for their children aged 6 months to 5 years. The main finding presented is that parents use social media not only for general health information seeking but also to triangulate and fact-check information given to them by their treating healthcare professionals. They also seek out alternative information before making health decisions for their children. This finding is significant as it lays the foundation for this thesis and broader work on why parents use social media for health information. It has been found that parents are not only seeking the information they would expect to find on a website but also seeking information in various forms from other parents that is not available elsewhere. Again, the majority of this is nested within information based on the lived experience of other parents and clearly demonstrates the utility of social media for these parents concerning their children's health journey.

This chapter has answered the following research questions

1. How many Australian parents use social media for health information for their children?
2. What are the characteristics, determinants and motivations of Australian parents that use social media for health information for their children?

This chapter has provided quantitative data on the Australian parents' characteristics, motivations, and sentiments of using social media for health information. The following chapter describes, via the use of qualitative methodology, Australian parents' use of social media for health information. As told in their own voices, the results add depth and enrichment to the statistical findings presented here.

## Chapter 5 – Qualitative Study

### 5.1 Introduction

This chapter presents the results of the qualitative phase of this thesis. It was initiated from the findings in the scoping review (Chapter 2) and quantitative study (Chapter 4) that showed Australian parents use social media to seek health information for their children. In this qualitative study, parents tell us in their own words their motivations and reasons and how they determine which sources of information to trust on social media, adding depth and enrichment to the quantitative findings of the previous and following chapters.

This qualitative phase used semi-structured interviews and reflexive thematic analysis (Braun & Clarke, 2021) for data collection and analysis.

Significant findings include uncovering what parents, in their own words, perceive to be lacking in their informational environment and clinical interactions, motivating their use of social media for health information for their child, both before and after consulting the health professional of their choice.

This paper meets the second and third objective for this research:

1. To determine the characteristics, determinants and motivations of Australian parents that use social media for health information for their children.
2. To explore how parents use social media to find health information for their children and which platforms they access.

### 5.2 Publication Details

This paper was submitted to *Social Media + Society* (IF: 5.2 ) in May 2024 and is currently under review.

Frey E, Bonfiglioli C, Frawley J. (2024) A Library of Parents: Australian parents' experience of health information and connection seeking on social media.

### 5.3 A Library of Parents: Australian Parents' Experience of Health Information and Connection-Seeking on Social Media

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#### **Abstract**

Parents are using social media for health information as it has become part of their information-seeking routine and is now highly integrated into society. Social media facilitates the sharing of vast amounts of information, including that based on lived experience, which may be insightful for parents with similar information needs. Nineteen parents from across Australia, recruited through social media, were interviewed about their experiences using social media for health information for their children (aged 0-18 years). Using Reflexive Thematic Analysis, two main themes were revealed: 1) On a mission – an at times overwhelming urge to obtain as much information as possible about every aspect of their child's health condition or diagnosis and 2) Sharing is caring – where parents sought support and a sense of community from other parents with similar lived experience. Further research is needed to understand the health literacy skills needed to navigate the social media

information terrain, current gaps in parents' health literacy, and how to most effectively and expeditiously bridge any gaps.

Keywords: parents; children; information seeking; social media; pediatrics; health behavior; infant; adolescent; health literacy; patient education; digital platform; information; public health

## **Introduction**

The ubiquity and influence of social media have transformed the landscape of health information, including for parents seeking guidance on their children's health.

Traditional methods of accessing health information, including the Internet, are being redefined by the unique attributes of social media platforms - namely, the advent of user-generated content. Notably, younger generations, referred to as "digital natives" (Prensky, 2001) or "social media natives" (Brandtzæg, 2016), gravitate toward social media as a primary source of information (Brandtzæg, 2016; Prensky, 2001). This paradigm shift is reflected in the increasing number of parents using social media for health-related enquiries (Bryan et al., 2020), signifying a widespread shift in general information-seeking behaviour among parents as a demographic.

The perfusion of social media into everyday life in Australia has been swift, especially among those considered social media natives. A 2020 study found that 85% of Australians aged 18–34 years reported using social media regularly, with 64% of this age group having an average of 5.2 social media apps on their phone, compared to 22% of Australians aged 35 and over (Commonwealth of Australia (Australian Communications and Media Authority, 2021), quantifying the widespread use of social media within this younger demographic. Additionally, the adoption of social media use among parents aged 18-34 as a predominant tool for seeking health information is continually growing. In the US, over 41 per cent of parents aged 18 to 35 (Lama et al., 2021) relied on social media for health-related information for their children, an increase of more than one-third from 7% in 2011 (Fox, 2011).

Australian parents face mounting challenges in accessing timely and affordable healthcare for their children. Factors such as geographic location, socioeconomic

disparities, and cultural considerations contribute to the complexities of healthcare access (Nolan-Isles et al., 2021). Particularly, marginalised groups encounter significant barriers. For example, 32% of Indigenous Australians who required healthcare in 2018-2019 did not access it due to a lack of cultural safety, including discrimination and language barriers, leading to substantial gaps in healthcare use between Indigenous and non-Indigenous Australians (Australian Institute of Health and Welfare, 2023). For parents living outside the major cities, prolonged wait times for consultations with general practitioners (GPs), specialists, and allied health professionals exacerbate parents' struggles in seeking healthcare for their children (Australian Bureau of Statistics, 2023) due to the medical workforce being concentrated in the capital cities (Phillips, 2019).

With the escalating challenges in accessing timely and affordable healthcare, including significant wait times for consultations with GPs, specialists (Mulraney et al., 2021), and allied health providers (McGill et al., 2020), parents are increasingly turning to social media as a vital resource for health information concerning their children (Bryan et al., 2020; Frey et al., 2023). This shift highlights the critical role of social media as a supplementary source of information, aiding parents in managing their children's health.

This study aimed to delve into the experiences and perceptions of parents who use social media for health information for their children (0-18 years). It acknowledges the evolving dynamics of parental health information seeking in an era of digital connectivity and healthcare disparities.

## **Methods and Materials**

### **Study Design**

This qualitative interview-based study explored how parents use social media to seek health information for their children from a phenomenological perspective.

Phenomenology is concerned with how individuals make sense of their lived experiences in regard to a specific concept or phenomenon, such as how parents make sense of their experience using social media for health information for their children (Creswell & Creswell, 2013, pp. 57–58). To build a picture of the phenomenon from the

ground up, phenomenology allows researchers to delve into what the participants have in common to describe a “universal essence” that is foundational to the way that everyone experiences the phenomenon (Creswell & Creswell, 2013, p. 58). The goal was to understand the individual experience of using social media for their children's health information and uncover any shared themes among the parents interviewed. Ethics approval was granted by the Human Research Ethics Committee (HREC) at the University of Technology Sydney (ETH21-5799).

Our research questions were:

RQ1: How do parents use social media for health information for their child?

RQ2: Which aspects of using social media for health information do parents find valuable?

RQ3: Which aspects of using social media for health information do parents find challenging?

RQ4: How do parents determine what information to trust and act on from social media?

## **Participants and Procedure**

Recruitment used purposive sampling to enlist Australian parents using social media for their child's health information. Inclusion criteria for eligible participants was that they were a parent of at least one child under 18 and sought health guidance via social media. Those unable to engage via Zoom/Skype or unwilling to record interviews (as a disability accommodation for the interviewer) were excluded. Recruitment involved posters and targeted social media ads (~\$300AUD) in 86 relevant Facebook groups across Australia. The first author distributed the recruitment poster to 86 Facebook groups that were location-based (for example, North Sydney Living) or child/parenting-specific (for example, Inner West Mums) across Australia's states and territories. Consent to participate was a clearly defined and separated process outlined by the authorising Ethics Committee to avoid the participants feeling any sense of duty, coercion or duress from the researchers. This was achieved by participants following a QR link on recruitment posters to a survey page on Qualtrics XM (Qualtrics XM, 2021), where the Participant Information Sheet (PIS) was provided for full disclosure, allowing them to make an informed decision to consent. Participants then indicated their



willingness to participate by providing their contact details for researchers to contact them to be interviewed on Zoom (Zoom, 2021). A total of 19 parents meeting the criteria were interviewed for this study, as shown in Table 5.1.

Table 5.1 Characteristics of Participants (n=19)

<b>Geographic location</b>	
Metro	13
Regional	6
Rural	0
<b>Level of Education</b>	
High School	1
TAFE	4
Undergraduate	3
Postgraduate	7
PhD	4
<b>Marital status</b>	
Single	0
Married/Partnered	18
Divorced	1
<b>Number of children</b>	
1	7
2	5
3	4
4	2
5+	0
<b>Child's health status</b>	
Generally healthy	12
Chronic condition	7
<b>Gender</b>	
Identify as Male	1
Identify as Female	18

Interviews spanned from 6 minutes to 44 minutes. All interviews were conducted by EF over Zoom, video and audio recorded and transcribed verbatim by EF with the participants' consent. Data was analysed iteratively by EF using NVivo12. All identifiable information was kept separate from the data collected, known only to the interviewer.

Inductive reflexive thematic analysis was used for this study as it was determined to be the most appropriate to answer the research question without knowing what the data collected would reveal about this unexplored phenomenon. Adhering strictly to the 6

steps of data analysis as outlined by Braun and Clarke (immersion, data coding, theme development, reviewing and refining themes, defining themes and report writing) analysis was led by EF after data collection had concluded. Following Braun and Clarke Reflexive Thematic Analysis methodology, we decided *in situ* after the 19<sup>th</sup> interview that there was enough data to see themes and patterns in common amongst the participants (Braun and Clarke 2019).

Data credibility and trustworthiness was considered with a variety of processes (Tuckett, 2005). Interviews were semi-structured and guided by a standardised interview guide (Appendix D). Internal validity was assured with EF transcribing the transcripts verbatim, while CB reviewed the transcripts and JF reviewed the (audio) interviews. Video and audio recording was done to ensure that any audio that was unclear could be lip-read for improved accuracy.

One-on-one interviews were chosen to allow for independent thought from the participants, avoiding 'group think' (MacDougall and Baum, 1997) and social agreement when being asked about their personal experiences. The final internal process involved JF and CB independently testing the themes identified by EF, to ensure that the data and themes matched.

Having the entire dataset for data immersion allowed for pattern recognition which was used for initial theme development. All authors were involved at various stages of the analysis using an essentialist/realist approach with semantic themes and refining themes.

Lastly, this research will be peer-reviewed before publication and dissemination (Tuckett 2005), adding extra validity from an independent and external review process.

The researchers on the team bring together expertise in Public Health and Media Studies. Two of the team previously were healthcare professionals (EF; JF), and one a medical journalist (CB). All have a keen interest in health communication.

## **Analysis**

A relativist/constructionist theoretical framework was used, deconstructing the participants' experiences to understand the phenomenon within the dataset (Braun & Clarke, 2021). Reflexive Thematic Analysis (TA) (Braun & Clarke, 2021) was used to analyse the data for this study, as it provides a structured process while allowing for flexibility. Reflexive TA requires that the researcher is "subjective, situated, aware and questioning" of the data, organically adjusting meaning and understanding as the researcher delves deeper into the data (Byrne, 2022). The authors adhered to the process of Reflexive TA, which consists of six phases: (1) data familiarisation, (2) data coding, (3) initial theme generation, (4) theme development and review, (5) theme refining, defining and naming, and (6) writing up. Using NVivo12, the inductive analysis allowed the data content to drive the code and theme development. The analysis aimed to capture and explore the participants' understanding and perspectives of their experience, focusing on latent meaning.

## **Results**

Without exception, all parents interviewed were motivated to independently find health information for their child, whether in the interim as a stopgap or because they wanted to self-manage the situation, to prepare for a health professional consult, or after consulting a health care professional. Parent's primary motivations were to seek information based on other parents' lived experiences – to peek into what could be possibly next for them, as it did for parents who are further ahead on the same health journey. All parents expressed a sense of self-efficacy, empowerment, or agency by using social media for health information. Alongside general health information, many parents found the support offered by other parents was mostly helpful or invaluable. There were occasional interpersonal conflicts; however, parents who experienced this showed self-protective measures such as setting purposeful boundaries to limit the chance of having a similar encounter again. In this section, we explore how parents are *on a mission* to find health information and, by doing so, are contributing to a community where their *sharing is caring*.

### **1. On a Mission**

Parents describe their motivation for using social media as *more is more* (i.e. driven to find as much information as possible, never too much). Others were *motivated to (self) manage* (i.e. managing the health concern until it was determined that professional input was required), or *mustering mettle* (i.e. preparing to advocate for their child). For others, it all became *much too much* (i.e. overwhelming).

### 1.1 *More is more*

Many parents felt that they could not get enough health information about their child's health condition of concern. Many were motivated (but not expectant) to find new and additional information that they had not been given by their treating health professional(s).

*I think like the effectiveness of it, you know, it's kind of at your fingertips, it's again information that you didn't know you didn't know, you didn't know you needed that information and strategies, you know, it's really practical things. (P1)*

The availability of health information from other parents on social media at times of need was attractive to parents.

*...it just comes up with things that you don't necessarily think of, like all the health information is fine, but you know, you're a parent, you're stressed out, and you sort of want to hear what other stressed-out parents are thinking themselves. (P13)*

Some parents specified that varying levels of perceived need and urgency motivated their use of social media to inform a health decision for their child. Some parents stated that they used social media specifically to ask questions about non-urgent or common childhood illnesses.

*Um, it really depends on what it is. So, if it's like a cold that is just not sort of behaving like a cold or a stomach bug, I will generally go to, umm, like a mother's group or an online forum. (P16)*

Several parents spoke of an element of chance or luck to have found particular information because they only came to know it by chance interactions on social media, and it came to be crucial to the treatment or management of their child's condition.

*I was just really, it was really fortunate that one of the allergy nurses ... happened to be in that (Facebook) group, and she saw my post, and she contacted me privately and said, 'Hey, at Westmead Hospital, we offer a programme specifically for severely allergic kids where we go into and actually help them figure out how to manage it'. And if that hadn't happened, I'm not sure how we would have figured it out to be honest. (P9)*

*...there was the laxative example where she (GP) was saying 'look laxatives are safe' and I tend to not believe her because I've seen these (Facebook) groups with thousands of thousands of people there been neurological damage to their children from mainstream laxatives for encopresis. (P3)*

In one example however, the urgent and desperate use of social media came after specialists had told a parent they had run out of treatment options for her child with leukemia. Being part of an international List Serv for childhood leukemia led her to discover a leukemia protocol not yet available in Australia that ultimately saved her child's life.

*There were a couple of occasions where I felt that being on that list actually saved his life. Yes. Because there was finding out about that drug. (P10)*

Social media was also shown to facilitate communication between parents and experts for rare diseases, as well as the communication of timely developments on rare diseases and their treatments.

*They're both incredibly rare (conditions), and they're unconnected. ... social media forms a massive part of our connection worldwide and in a global community. (P12)*

*I still am on the Facebook page, and I still find out with these other ways we can treat it, what's new treatment that's coming in. I'm constantly keeping informed from social media about that. (P4)*

## 1.2 Motivated to (self) manage

Parents spoke of using social media to manage their child's health independently or until health care was wanted or needed. Several parents spoke of how social media is their first "port of call" for health information when concerned about their child's health rather than their usual healthcare professionals.

*I think the day and age of your doctor directing you as to where you should go is probably past, or it is for me; I don't see my doctor as necessarily the first port of call by any means when it comes to any type of health information or referrals. (P17)*

*... that's why I, I have valued social media in that, instead of having to physically go to a doctor or pharmacy for a simple question like 'Is this, what kind of rash is this?' or 'has anyone else experienced this sleeplessness at this age group?' It's just, I suppose, a first port of call to check uhm, those community mothers groups in that, has anyone else experienced, have they got advice and who they sought advice from? (P8)*

Parents also spoke of social media enabling them to "self-triage" and learn about interim self-care strategies until they could consult their healthcare professional, especially when access to their usual healthcare was a matter of days, weeks, or months away.

*I kind of use them (social media medical professional influencers) quite frequently and as a kind of first stop to know if I need to escalate or kind of, investigate further, so they've been quite good. (P5)*

*I think it (social media) can help you start to work out what [health condition] actually you're dealing with. (P2)*

For others, choosing to first consult social media for health information was a form of empowerment, agency or parental self-efficacy due to previous unsatisfactory experiences or a desire to improve their child's present experience.

*I would then obviously make a decision [about] whether we need to go to a GP, and I usually let that guide why I'm going to the GP, so I will tell them ... 'I've researched and this is what I think it is' and that comes from being uhm, a little bit let down from GPs in the past and not having trust for them so I feel like I do the research what I can online and social media first. (P4)*

*...it certainly gave me a greater sense of agency in the process. Rather than being the person that just tagged along and had to fit in with whatever the go was. I could actually direct some of the traffic and also try to make him (son) a happier participant. (P10)*

*Probably the only other thing I'd say is maybe a positive is I do feel less disempowered, maybe a little bit more empowered with the information I get and the segue that it creates into something else is the other benefit. (P12)*

### *1.3 Mustering mettle*

Parents, particularly of children with rare diseases, used social media to prepare and, in some cases, steel themselves for their upcoming consultation with their healthcare professional. Parents felt a deep sense of responsibility to be armed with information (and support) to fight for their child's best interest.

*I read a lot of that and then I kind of felt like I knew what questions to ask when we saw my daughter specialist about what to do, I have felt a bit more confident to ask the questions. (P9)*

*So ever since then, I kind of doubted what doctors tell me and so I always thought 'right' you know 'from now on if it's gonna be, I'm going to Google and look on social media and then I will ask the doctor and I've got knowledge before I go'. (P4)*

For others, it was about being in a better position to advocate for their child's care.

*...the main thing for me was being able to talk to people who provided targeted information and also shared their own personal experiences.*

*Because sometimes when a hospital will do something is a way that works for them. It's not necessarily a way that works for you or your child. (P10)*

It was not uncommon for parents to educate their treating healthcare professionals about what could be expected going forward for their child and their condition. This was informed by the experiences of other parents shared on social media.

*I have taken stuff (information found on social media) to the doctor, to the neurologist, and before that, to the team. Yeah. And sometimes they've gone, 'yeah, I haven't heard of that. And I'll check it out and get back to you.' ...For us, it's [social media] kind of worked well because I've been able to watch everybody else's responses to different medications before we've tried it. So, I've sort of learned some of the pitfalls or side effects. (P19)*

#### *1.4 Much too much*

Parents' use of social media was not without its challenges. Parents spoke of feeling overwhelmed by the amount of information they encountered and how it challenged their health literacy skills. Parents spoke of conflicting information, getting distracted by vast amounts of information, and unhelpful information that could lead to wasted time, inadvertent obsession or catastrophising.

*All the garbage you've got to wade through when you are trying to be discerning. There's a lot of garbage to wade through. (P15)*

Some parents also spoke of personal challenges and negative impacts on their lives that resulted from participating in social media, including being exposed to distressing content, judgement from other parents and witnessing conflict between the other parents. This led to some parents experiencing distress after using social media for health information.

*... I think I was just already so stressed and so worried and feeling so guilty that I couldn't figure out how to feed my child properly, uhm you know, that it was just really the last thing I needed was to have people yelling, shouting at me in caps that, you know, that I was being stupid to even consider giving her formula. (P9)*



*At the moment, I think I've hidden all of the pages just because I just need to have that break from it... But, yeah, I have had to hide them because sometimes it can get overwhelming. (P6)*

## **2. Sharing is Caring**

Parents spoke of a sense of community found and grown on social media. This community would often be more integral to the parent's well-being than the parents' offline social circles. The *sharing understanding and creation of supportive community* was underpinned by the *sharing knowledge and know-how* from other parents in the group. Some sharing was reciprocal, and some were unidirectional by way of lurking. Other parents shared in a synchronous manner, while others sought support asynchronously. All support that parents received was held in high regard and credited with being essential to the progress of their health information journey.

### *2.1 Sharing understanding and creating a supportive community*

Parents spoke of the intrinsic *simpatico* they felt with other parents who understood their situation. This enabled parents to create communities with other parents to support and guide each other emotionally. Being understood by other parents was fundamental to the sense of connection parents had with others on social media. This was the case regardless of the parents' support networks in the 'real' world because connecting with parents who had a shared understanding of what they were going through with their child's condition or illness was seen as invaluable.

*When you've got a kid that's got an invisible chronic illness, if you like, it can be really difficult. So, I guess that level of social support is probably the most important. (P19)*

*...that's the best thing, is learning that you know, these people going through exactly the same thing as you. (P4)*

Finding support from other parents was a significant motivator for most parents in our study, especially initially. However, some parents stated that as they became more embedded within the communities on social media, they made an effort to support

and share their knowledge with other parents, especially those new to the shared journey.

*...they're essentially just a big community of parents who either have babies around the same age or have babies a bit older, who have been there, experienced that and got out the other side. So, I found the community aspect of it really reassuring and supportive. (P14)*

*I always try and write on there (the Facebook group), I'm not a big social media person personally, but I do try to write on there 'coz I know it gives comfort to to (sic) new parents that are discovering stuff and that kind of ... (P4)*

Community was built around a shared understanding unlikely to be accessible in the real world, especially for parents of children with very rare diseases due to geographical constraints. These communities allowed parents to keep connected as their children grew up and reached different stages of childhood and adolescence.

*I think it's, it can be a collective group of experienced people, uhm, and when you have something, like with my daughter's food allergies, it can be a bit obscure, she's got some unusual allergies and it can be hard to find people who get it, who understand what's going on, and just as she moves through different stages of childhood, it can be hard finding people who have similar experiences of how things change over time, and that's where it's been really helpful. (P9)*

## *2.2. Sharing knowledge and know-how*

Distinct from emotional support, parents found social media to be a source of practical know-how and solution-orientated information based on other parents' lived experience. Parents sought out and valued this practical information, which is not readily available outside of the social media space.

Insights from other parents on social media were particularly sought after. These experiences were held in high regard, with some parents saying they valued this information more than information from their treating health professional(s).

*I've found the problem with allergy type stuff is a lot of GPs, they're just not familiar with it, they just don't have enough knowledge about it... Yeah, so that's sometimes why I have given up on the GPs and gone to actually groups that have a bit more experience with that specific condition. (P9)*

*So there's a few sort of, unfortunately, well-seasoned 'Heart Mums' on Instagram who have a really big knowledge on who probably know more than a lot of the nurses that work in the heart departments. (P16)*

Most parents spoke of how other experienced parents on social media had taught them information that had not been (and was not expected to be) discussed with them by their health professionals but was essential to their ability to care optimally for their child. Information from other parents centred around 'tips and hacks' was the most common.

*...it's really practical things like buying a (sic) animal cooling mat for your baby when it's hot in summer to put in the pram. (P1)*

*I've just reduced his stress, reduced my stress, and may do a job 50% faster [maintaining a port site]. That came from my Listserv that was like, 'you don't actually have to do it their way... as long as you get the same result'. (P10)*

Participants highlighted how other parents provided valuable tips on navigating the health system, locating available resources that parents were unaware of previously, or finding ways to get the outcome needed from alternative avenues.

*...we were looking for OTs. The waitlist is astronomical up here at the moment for them, and someone (in a local social media group) suggested instead going to see a paediatric physio. Umm and she's been incredible, and it's been exactly what we've needed. We still are on waitlists for OTs. (P6)*

Parents also sought specific information to guide or reassure them about their health decisions for their child.

*...I guess that's the main thing 'coz you don't want to hear over and over again like 'just apply this cream, just apply this cream' like using experience, for example you want to hear like 'I put this cream on for a week and then it started to help but I also did this in this and that also helped' like you sort of want that information. (P13)*

Parents spoke about how learning from parents and their children in similar situations on social media influenced and guided their own health decisions.

*I've had read on social media that a lot of parents were getting more traction with Augmentin and we just swapped to Augmentin about a month ago and it's made a massive difference. So, I mean, you know, I wouldn't have known that I would've just gone off what we were supposed to take in and probably battled through. (P4)*

Finally, parents spoke of how seeing other children's health journeys showed them in practical ways the possible future events for their child's diagnosis or condition.

*I've been able to say sometimes, too, my son's had these side effects to the doctor, and they'll go, 'Well, I haven't heard of anybody else'. And I go, 'Well, in the support group, it's going on', do you know what I mean? Because not all doctors, I guess, share information equally or have that access to that sort of client database either. (P19)*

*I would say to just look at, as the condition continues, and as we're treating it just looking at the progress and making sure that, you know, it's following the expected path. (P11)*

## **Discussion**

An increased ability to obtain, comprehend, and apply health information boosts confidence and autonomy in health-related decisions (Nutbeam, 2000). Previous research has shown that parents' motivations to use social media for health information include seeking additional health information that was not provided in consultation (Frey et al., 2023; Willis et al., 2023) and the convenience and availability of social media (Clapton-Caputo et al., 2020; Garcia et al., 2019).

Social media's ability to create communities of people, regardless of geographical location, allows information to be disseminated quickly and democratises who can access it and when it can be accessed (van Dijck & Poell, 2013). Social media facilitates interactions between strangers at an unprecedented scale (Neubaum & Krämer, 2017; Sutcliffe et al., 2011), enabling parents to find health information based on the lived experience of other parents, no matter how niche their circumstances, as we learned from the parents in our study.

When parents spoke of the challenges of using social media, they revealed two discrete but related domains – the interpersonal challenges when interacting on social media and its impact on them. Using social media for health information requires an understanding of the social media landscape and its implicit and nuanced rules of engagement, especially when exploring health information that is political or ideological (Bradshaw et al., 2020). Unfortunately, as our participants explained, parents can find themselves the target of bullying and harassment, with name-calling and purposeful embarrassment being common forms of harassment (Vogels, 2021). These experiences can lead to negative impacts on mental health (extending into the parent's real life away from social media), resulting in anxiety, depression and poor job performance (Olpin et al., 2023), as well as feeling judged, maligned or bullied (Price et al., 2018). Parents in our study reported traumatic experiences while interacting on social media platforms and sometimes having to take time away from social media to protect themselves from distress.

Social media disseminates massive volumes of information of varying quality, making it challenging (and sometimes overwhelming) for parents to find, understand and evaluate. Parents in our study spoke of strategies to limit the intrusiveness of social media, including opting out of 'following' groups to keep their feeds clear and having time away from social media as a purposeful strategy to limit the exposure that led to distress, either as a result of information overload, or complications arising from interacting on social media (i.e. trolling, brigading) (Pew Research Center, 2021).

Parents' adoption of a fresh method for seeking health information on social media, aiming to 'access, understand, and use' (Nutbeam, 2008) information while actively engaging with the healthcare system, marks a novel frontier in health literacy. This shift has emerged from social media's role in democratising information, allowing more comprehensive access and participation in health-related knowledge. Parents seek out and place significance on others' lived experiences in a direct shift away from the positivist paradigm upon which evidence-based medicine was founded and has continuously operated (Bertolazzi et al., 2023). Increased access to social media and the capacity of parents to use health information has enhanced personal autonomy and empowerment (Nutbeam, 2000).

Health literacy frameworks until now have focussed on the health literacy skills needed for individuals to 'access, understand, appraise and use information' from traditional sources (Nutbeam, 2000) or digital variations of those same sources (Liu et al., 2021), using health literacy skills that are applied in a sequential and consecutive process (Sørensen et al., 2012). However, health information on social media differs from the traditional health information context in two crucial ways. Firstly, health information on social media is not static due to its dynamic nature, which sees information and its context constantly changing with the flow of 'conversation' (interaction), which can lead to misrepresentation of health information (Terry, 2019). In contrast, traditional health information (including digital sources such as webpages) is static - once published, the content does not change (Keselman et al., 2019) without due process by the information gatekeepers. Secondly, when considering information about lived experience, those who are the gatekeepers of the information are also the source of that information – self-styled experts in their own experience (Bertolazzi et al., 2023), meaning that there is no independent verification or peer review process for this information. As a result, accurate and trustworthy health information is difficult and complex for parents to identify, especially when the information is conveyed within a dialogue that introduces layers of nuance, emotion, complexity and influence (Frey et al., 2022).

Parents may find themselves being 'influenced' to their detriment by their parenting 'peers' (Willis et al., 2023) due to not having the experience or health literacy skills to

identify when the information is designed to persuade through narrative rather than to inform objectively (Dahlstrom, 2021). Parents can experience confusion when using social media for health information, with user-generated resources that are well-developed and aesthetically pleasing, appearing to have the 'authority' that traditional publishing bestows, but without the independent and expert fact-checking that the traditional publishing process includes (Bertolazzi et al., 2023). All these factors complicate the health information landscape that parents navigate when using social media for health information.

Parents use social media because it feels approachable and easier to understand, often through conversation or storytelling from other parents. While stories make complex information easier to understand (Bullock et al., 2021), they also make it easier for people to be persuaded (Bullock et al., 2021). They may also distort their perceptions (Dahlstrom, 2021). For example, those with low numeracy skills have been shown to use stories (lived experience perspective of risk and likelihood) as evidence (Dieckmann et al., 2009) and to estimate how often an event may occur, as opposed to the real-life absolute risk of an event (Betsch et al., 2012). This results in parents obtaining a skewed perspective about the likelihood of an event happening, as those who were not impacted are not accounted for in the estimation of likelihood – this is also an example of survivor bias (van Rein et al., 2014). These factors, together with findings that show that people with lower health literacy may trust health information from social media in preference to information provided by their treating health professionals (Chen et al., 2018), may impact child health outcomes.

Our study highlights why parents use social media and the factors they consider valuable and challenging about its use for health information. However, the health literacy skills required to seek information on social media and navigate its landscape still need to be understood compared to the traditional health literacy skills needed for other health information formats. Understanding how parents interpret and use health information from social media is crucial as it significantly affects children's well-being, family dynamics, the involvement of healthcare professionals, and, ultimately, the healthcare system. Consequently, until a more precise grasp of how health literacy impacts a parent's experience when using social media for health information to

underpin health literacy interventions, children remain at risk of poorer health outcomes due to their parent's insufficient health literacy skills tailored for social media environments.

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The authors report that there are no competing interests to declare.

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## 5.4 Chapter Conclusion

This chapter presented a thematic analysis of 19 parents' semi-structured interviews to explore their reasons (in their own words) for using social media for health information for their children.

In this chapter, the following thesis research questions were answered:

1. What are the characteristics, determinants and motivations of Australian parents that use social media for health information for their children?
2. How do Australian parents use social media to find health information for their children and which platforms do they access?

Two themes emerged from the data – “on a mission” (information seeking) and “sharing is caring” (support seeking). This qualitative data expands and elaborates on the findings from the quantitative data in the previous chapter, with parents explaining their reasoning and rationale for their choice to use social media for health information. The results of this chapter show that parents are not only motivated to use social media for health information seeking but also to seek support and insight from the lived experience of other parents, which would not be available to them without social media.

The next chapter (Chapter 6) is the final results chapter, where parents' health literacy and critical thinking are investigated to determine if they have any impact on parents' use of social media, their platforms of choice, and whether it impacts parents' use of social media generally or before or after a consultation with a health professional.

## Chapter 6 – Quantitative Study 2

### 6.1 Introduction

This chapter presents the final results paper from the quantitative phase of this thesis. It was initiated from the scoping review and qualitative study finding that parents' health literacy skills are not where they need to be for safe information seeking on social media. This study aimed to quantify the health literacy and critical thinking of parents who use social media for health information by using validated scales in order to determine if a parent's health literacy or skills in critical thinking are a key determinant in their use of social media for health information.

This quantitative phase used statistical analysis to derive results, including descriptive analysis for sociodemographic data,  $\chi^2$  tests of association to establish significance, and logistical regression to determine predictors.

The key finding from this study was that there is a direct, inverse relationship between a parent's level of health literacy and their use of social media across all platforms and health information-seeking scenarios (general health information-seeking, as well as before and after consultations with health professionals).

This paper meets the third, fourth and fifth objective for this research:

1. To explore how parents use social media to find health information for their children and which platforms they access.
2. To discover if a parent's health literacy impacts their use of social media for health information for their children.
3. To find out if a parent's critical thinking ability impacts their use of social media for health information for their children.

### 6.2 Publication Details

This paper was submitted to Public Health Research and Practice (IF: 4.4) in May 2024 and is currently under review.

## 6.3 Parental Health Literacy and Critical Thinking When Seeking Health Information on Social Media: An Australian Cross-sectional Study

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### Abstract

**Objectives and importance of study:** To investigate which social media Australian parents use for health information and how health literacy and critical thinking skills affect social media use, including after a health consultation.

**Study type:** Representative cross-sectional study.

**Methods:** A survey was conducted in 2021 with a representative sample of 1000 Australian parents whose youngest child was aged six months to 5 years and who had an active social media profile. Questions explored demographics, social media use, and how parental skills relate to social media use. Two validated scales were used: the Parenting Plus Skills Index (PPSI) to measure parental health literacy and the Critical Thinking Disposition Scale (CTDS). The analysis included descriptive statistics,  $\chi^2$  associations and logistic regression.

**Results:** Most parents ( $n = 822$ , 82.2%) used social media for health information. Facebook was the most accessed platform (78.6%,  $n = 646$ ). Health literacy was a critical determinant of parents' use of social media. For every 1-point increase in PPSI, parents were less likely to use social media generally for health information (OR: 0.792; 95% CI 0.730, 0.859  $p < 0.001$ ), and before (OR: 0.773; 95% CI 0.713, 0.838  $p < 0.001$ ) or after a healthcare consult (OR: 0.725; 95% CI 0.669, 0.786  $p < 0.001$ ). Critical Openness (CO) was associated with parents who use Facebook (Moderate CO: OR: 0.281; 95% CI 0.118, 0.671  $p = 0.004$ ; High CO: OR: 0.406; 95% CI 0.238, 0.694  $p < 0.001$ ) and Instagram (Moderate CO: OR: 0.302; 95% CI 0.119, 0.767  $p = 0.012$ ).

**Conclusion:** Parents with higher levels of health literacy are less likely to use social media for health information before or after consulting a health professional.

**Key points:**

- Parent's level of health literacy is the key determinant for using social media for health information.
- Informs health professionals that parents consult social media for health information, even post-consultation, and reliance on social media could be reduced by checking that health advice is understood.

**Keywords** – social media, parenting, information-seeking behaviour, child, infant, health literacy, patient education, digital platform, information, health information, public health.

## **Introduction**

Parents often seek health information on social media, especially when managing their children's health.<sup>1</sup> Factors driving this include ease of access and availability of bespoke caregiving advice and supportive communities sharing insights from lived experience.<sup>2</sup> However, social media health content can be less reliable than traditional health information<sup>3</sup> leading to the possible use of unproven treatments,<sup>4</sup> delaying seeking treatment<sup>5</sup> or not using healthcare appropriately.<sup>6</sup>

Parents need health literacy to determine what information is evidence-based or high-quality. In 2006, 60% of Australian 15-74-year-olds were found to lack adequate health literacy.<sup>7</sup> Health literacy encompasses "cognitive and social skills shaping one's motivation and ability to access, comprehend, and utilise health-related information".<sup>8</sup> Parental health literacy significantly impacts child health outcomes, parental care such as oral health, nutrition, and exercise<sup>9</sup>, and the management of complex health conditions.<sup>10</sup>

This representative study investigates which social media platforms Australian parents use for health information and whether their health literacy and critical thinking skills affect this use in general and before or after visiting a health professional.

Our research questions were the following:



- RQ 1:** Which social media platforms are parents using for health information?
- RQ 2:** How do parental health literacy and critical thinking impact which social media platforms parents use for health information?
- RQ 3:** Does a parent's health literacy and critical thinking impact whether they use social media for health information generally, before, and after a consultation with a health professional?

## **Materials and Methods**

### *Study Design and Participants*

We invited parents in Australia to complete the survey in November and December 2021. A "parent" was defined as anyone aged 18 years or older who was a biological parent, adoptive parent, guardian, or caregiver. Quality Online Research (QOR) administered the survey using their nationwide panel. Eligible participants were Australian residents with their youngest child aged six months to 5 years who had an active social media profile at the time.

### *Sample size*

We used a sample size of 1000 parents, providing a half-confidence interval width of approximately 3.1%.

### *Sampling*

QOR stratified the sample following the 2016 Australian census<sup>11</sup> to ensure representation across states, territories, and gender. Participants received a small incentive (approximately AUD 2.80 [USD 1.80]).

### *Materials*

The online survey comprised 47 items. Demographic questions included gender, socio-economic status, marital status, education, language spoken at home, country of birth, age, number of children and state of residence (metro, regional or rural designation). We used postcodes to determine the Australian Bureau of Statistics Socio-Economic Indexes for Areas (SEIFA).<sup>12</sup> We matched postcodes to the Index of Relative Socio-economic Advantage and Disadvantage (IRSAD) to determine the IRSAD of each participant.<sup>12</sup> Some postcode data (26/1000, 2.6%) was missing, potentially due to

participant error, resulting in 974 valid SEIFA results. These were treated as missing variables.

The survey consisted of questions from two validated surveys<sup>13,14</sup> and questions informed by our scoping review.<sup>2</sup> The validated scales were: the PPSI<sup>15</sup> to measure parenting literacy and the CTDS<sup>16</sup>.

#### *Health information resources*

We asked parents which social media platforms they use for information about their child's health and how they use those platforms.

#### *Social media health information-seeking habits*

We asked parents about their general child health information-seeking habits and whether they used social media before or after attending their most recent child's health consultation.

#### *Parental health literacy*

We measured parents' health literacy using the PPSI<sup>15</sup>, a validated 13-item performance-based scale that assesses health literacy in caregiving tasks for children aged 0-15. It tests the capacity to interpret the NSW Immunisation Schedule and medication labels and to perform simple maths. Parents were also asked to select which of three websites from a Google search screenshot would provide the most unbiased information about starting solids and rank these from best to worst for information quality.

#### *Critical thinking*

Parents' critical thinking was assessed with the 11-item CTDS<sup>16</sup> which has sub-scales measuring Critical Openness (CTDS-CO) and Reflective Skepticism (CTDS-RS).

#### *Data Analysis*

We pilot-tested the survey with 122 participants. The survey was live from November to December 2021, collecting a further 878 eligible responses for a total of 1000.

The data was analysed using IBM SPSS Statistics for Mac v.28. Chi-squared tests for associations between parental demographics and platform use were used.

We used logistic regression to assess whether parental health literacy or critical thinking disposition influenced their social media use for health information. A logistic regression was conducted to ascertain if a parent's health literacy affected their health information seeking on social media before or after consulting a health professional, adjusting for gender, SEIFA, marital status, level of education, language spoken at home, country of birth and age. Statistical significance was set at  $p < 0.05$  for the most parsimonious model.

### *Ethics*

Ethical approval was provided by the University of Technology Sydney Human Research Ethics Committee (ETH21-6598).

## **Results**

### *Demographics*

Demographics are presented in Table 6.1.

Table 6.1 Demographics

	Total N =1000	Total %
<b>Gender</b>		
Male	413	41.3
Female	575	57.5
Other*	12	1.2
<b>SEIFA^</b>		
Highest quartile	213	21.3
2nd quartile	218	21.8
3rd quartile	217	21.7
Lowest quartile	326	32.6
<b>Marital status</b>		
Never married / single	207	20.7
Married/partnered	754	75.4
Separated/widowed	39	3.9
<b>Education</b>		
High school	273	27.3
Trade (vocational training)	193	19.3
University	534	53.4
<b>Language spoken at home</b>		
English	955	95.5
Other	45	4.5
<b>Country of Birth</b>		
Australia	906	90.6
Other	94	9.4
<b>Age</b>		
18-29	308	30.8
30-39	412	41.2
40-49	325	32.5
50+	45	4.5
<b>Location by State</b>		
New South Wales	322	32.2
Australian Capital Territory	13	1.3
Queensland	205	20.5
Victoria	269	26.9
South Australia	75	7.5
Tasmania	29	2.9
Northern Territory	4	0.4
Western Australia	83	8.3
<b>First child</b>	769	76.9
<b>Metro</b>	601	60.1

\* Non-binary/Chose not to disclose.

^ SEIFA (IRSAD): Socio Economic Index for Areas (Index for Relative Socio-Economic Advantage and Disadvantage) 974 valid responses.

*Parents who seek health information for their children on social media*

Over 80% (82.2%  $n = 822$ ) of parents of children aged 6 months to 5 years reported using social media to find child health information (Table 6.2). Parents born in Australia were more likely to use social media ( $n = 754$ , 83.2%) than parents born outside Australia ( $p = 0.009$ ). No other demographics predicted such use of social media.

For platform use by demographic, please refer to Appendix 1.

Table 6.2 Platform use by demographic

	Use social media n = 822 (%)	p	Facebook n = 646 (%) n (%)	p	YouTube n = 532 (%) n (%)	p	Instagram n = 413 n (%)	p	Twitter # n = 234 n (%)	p	Linked In n = 217 n (%)	p	Pinterest n = 163 n (%)	p	Total N = 1000
<b>Gender</b>		0.680		0.190		<0.001		0.264		<0.001		<0.001		0.265	
Male	340 (82.3)		254 (61.5)		253 (61.3)		183 (44.3)		139 (33.7)		121 (29.3)		76 (18.4)		413
Female	471 (81.9)		383 (66.6)		272 (47.3)		225 (39.1)		89 (15.5)		95 (16.5)		86 (15.0)		575
Other*	11 (91.7)		9 (75.0)		7 (58.3)		5 (41.7)		6 (50.0)		1 (8.3)		1 (8.3)		12
<b>SEIFA^</b>		0.176		0.377		0.009		0.004		<0.001		0.356		0.018	
Highest quartile	179 (84.0)		205 (96.2)		190 (89.2)		161 (75.6)		104 (48.8)		78 (36.6)		70 (32.9)		213
2nd quartile	178 (81.7)		133 (61.0)		96 (44.0)		82 (37.6)		40 (18.3)		39 (17.9)		30 (13.8)		218
3rd quartile	168 (77.4)		144 (66.4)		115 (53.0)		86 (39.6)		39 (18.0)		44 (20.3)		27 (12.4)		217
Lowest quartile	275 (84.4)		146 (44.8)		121 (37.1)		75 (23.0)		41 (12.6)		49 (15.0)		32 (9.8)		326
<b>Marital status</b>		0.644		0.424		0.208		0.009		<0.001		0.036		0.195	
Never married / single	169 (81.6)		130 (62.8)		101 (48.8)		68 (32.9)		30 (14.5)		36 (17.4)		26 (12.6)		207
married/partnered	623 (82.6)		494 (65.5)		413 (54.8)		332 (44.0)		198 (26.3)		177 (23.5)		132 (17.5)		754
separated/widowed	30 (76.9)		22 (56.4)		18 (46.2)		13 (33.3)		6 (15.4)		4 (10.3)		5 (12.8)		39
<b>Education</b>		0.052		0.794		<0.001		<0.001		<0.001		<0.001		0.057	
High school	219 (80.2)		172 (63.0)		124 (45.4)		78 (28.6)		38 (13.9)		45 (16.5)		36 (13.2)		273
Trade	150 (77.7)		127 (65.8)		77 (39.9)		58 (30.1)		23 (11.9)		27 (14.0)		26 (13.5)		193
University	453 (84.8)		347 (65.0)		331 (62.0)		277 (51.9)		173 (32.4)		145 (27.2)		101 (18.9)		534
<b>Language spoken at home</b>		0.693		0.767		0.985		0.155		0.046		0.931		0.168	
English	786 (82.3)		616 (64.5)		508 (53.2)		399 (41.8)		229 (24.0)		207 (21.7)		159 (16.6)		955
Other	36 (80.0)		30 (66.7)		24 (53.3)		14 (31.1)		5 (11.1)		10 (22.2)		4 (8.9)		45
<b>Country of Birth</b>		0.009		0.284		0.384		0.005		0.002		0.372		0.032	
Australia	754 (83.2)		590 (65.1)		486 (53.6)		387 (42.7)		224 (24.7)		200 (22.1)		155 (17.1)		906
Other	68 (72.3)		56 (59.6)		46 (48.9)		26 (27.7)		10 (10.6)		17 (18.1)		8 (8.5)		94
<b>Age</b>		0.120		0.516		0.264		0.502		<0.001		0.143		0.893	
18-29	255 (82.8)		189 (61.4)		167 (54.2)		127 (41.2)		49 (15.9)		54 (17.5)		48 (15.6)		308
30-39	343 (83.3)		270 (65.5)		207 (50.2)		170 (41.3)		97 (23.5)		102 (24.8)		71 (17.2)		412
40-49	193 (59.4)		158 (48.6)		136 (41.8)		102 (31.4)		77 (23.7)		51 (15.7)		36 (11.1)		325
50+	31 (68.9)		29 (64.4)		22 (48.9)		14 (31.1)		11 (24.4)		10 (22.2)		8 (17.8)		45
<b>Location by State</b>		0.708		0.021		0.282		0.284		0.075		0.813		0.413	
New South Wales	268 (83.2)		208 (64.6)		187 (58.1)		139 (43.2)		85 (26.4)		59 (18.3)		47 (14.6)		322
Australian Capital Territory	10 (76.9)		7 (53.8)		4 (30.8)		3 (23.1)		4 (30.8)		3 (23.1)		2 (15.4)		13
Queensland	174 (84.9)		147 (71.7)		110 (53.7)		93 (45.4)		46 (22.4)		47 (22.9)		38 (18.5)		205
Victoria	214 (79.6)		153 (56.9)		132 (49.1)		103 (38.3)		54 (20.1)		64 (23.8)		2 (0.7)		269
South Australia	59 (78.7)		46 (61.3)		38 (50.7)		26 (34.7)		12 (16.0)		17 (22.7)		12 (16.0)		75
Tasmania	25 (86.2)		22 (75.9)		15 (51.7)		10 (34.5)		7 (24.1)		8 (27.6)		16 (55.2)		29
Northern Territory	4 (100)		3 (75.0)		3 (75.0)		3 (75.0)		3 (75.0)		1 (25.0)		1 (25.0)		4
Western Australia	68 (81.9)		60 (72.3)		43 (51.8)		36 (43.4)		23 (27.7)		18 (21.6)		3 (3.6)		83
<b>First Child</b>	623 (81.0)	0.074	492 (64.0)	0.454	404 (52.5)	0.442	307 (39.9)	0.106	183 (23.8)	0.588	157 (20.4)	0.072	130 (16.9)	0.345	769
<b>Metro</b>	498 (82.9)	0.502	370 (61.6)	0.014	328 (54.6)	0.285	260 (43.3)	0.122	150 (25.0)	0.153	136 (22.6)	0.382	108 (18.0)	0.079	601

# Twitter data collected before change to X \* non-binary/Chose not to disclose. ^ SEIFA (IRSAD): Socio Economic Index for Areas (Index for Relative Socio-Economic Advantage and Disadvantage). 974 valid responses.

### *Health literacy and critical thinking*

The PPSI score was a significant predictor ( $p < 0.001$ ) for parents' use of social media for health information across all platforms (Table 6.3). Parents with higher PPSI health literacy were less likely to use social media for health information than people with lower PPSI scores. For every 1-point increase in parental health literacy, parents were less likely to use Facebook (OR 0.869; 95% CI 0.819, 0.922  $p < 0.001$ ), YouTube (OR 0.829; 95% CI 0.782, 0.880  $p < 0.001$ ); Instagram (OR 0.786; 95% CI 0.738, 0.836  $p < 0.001$ ), Twitter (OR: 0.769; 95% CI 0.714, 0.829  $p < 0.001$ ), LinkedIn (OR: 0.892; 95% CI 0.835, 0.954  $p < 0.001$ ) and Pinterest (OR: 0.809, 95% CI 0.750, 0.873  $p < 0.001$ ).

The Critical Openness subscale (CTDS-CO) was a predictor for parents' use of Facebook and Instagram (Table 6.3). Parents with moderate Critical Openness were 71.9 % less likely to use Facebook for health information (OR: 0.281; 95% CI 0.118, 0.671  $p = 0.004$ ). Parents with high Critical Openness were 59.4% less likely to use Facebook for health information when compared with parents with low Critical Openness scores (OR: 0.406; 95% CI 0.238, 0.694  $p < 0.001$ ). For Instagram, moderate Critical Openness was the only aspect of critical thinking found to be significant: parents with moderate Critical Openness were 69.8% (OR: 0.302; 95% CI 0.119, 0.767  $p = 0.012$ ) less likely to use Instagram for health information than parents with low Critical Openness.

Table 6.3 Parental health literacy and critical thinking impact on use of social media platform for health information

	Facebook			Instagram			YouTube			Twitter#			LinkedIn			Pinterest		
	OR	95% CI	<i>p</i>	OR	95% CI	<i>p</i>	OR	95% CI	<i>p</i>	OR	95% CI	<i>p</i>	OR	95% CI	<i>p</i>	OR	95% CI	<i>p</i>
<b>PPSI*</b>	<b>0.869</b>	<b>0.819-0.922</b>	<b>&lt;0.001</b>	<b>0.786</b>	<b>0.738-0.836</b>	<b>&lt;0.001</b>	<b>0.829</b>	<b>0.782-0.880</b>	<b>&lt;0.001</b>	<b>0.769</b>	<b>0.714-0.829</b>	<b>&lt;0.001</b>	<b>0.892</b>	<b>0.835-0.954</b>	<b>&lt;0.001</b>	<b>0.809</b>	<b>0.750-0.873</b>	<b>&lt;0.001</b>
CTDS*																		
Low	Ref	Ref	0.933	Ref	Ref	0.183	Ref	Ref	0.079	Ref	Ref	0.334	Ref	Ref	0.064	Ref	Ref	0.918
Moderate	0.964	0.322-2.887	0.948	0.465	0.144-1.497	0.199	0.363	0.120-1.094	0.072	0.364	0.088-1.496	0.161	0.175	0.039-0.777	0.022	1.269	0.259-6.208	0.769
High	0.899	0.475-1.699	0.742	0.544	0.283-1.045	0.068	0.505	0.272-0.938	0.031	0.604	0.271-1.345	0.217	0.539	0.258-1.125	0.100	0.972	0.408-2.316	0.948
CTDS_CO*																		
Low	Ref	Ref	<b>0.002</b>	Ref	Ref	<b>0.042</b>	Ref	Ref	0.687	Ref	Ref	0.585	Ref	Ref	0.357	Ref	Ref	0.375
Moderate	0.281	0.118-0.671	<b>0.004</b>	0.302	0.119-0.767	<b>0.012</b>	0.791	0.333-1.876	0.594	0.943	0.318-2.799	0.915	1.924	0.619-5.979	0.258	0.903	0.268-3.039	0.869
High	0.406	0.238-0.694	<b>&lt;0.001</b>	0.679	0.400-1.153	0.152	0.799	0.480-1.329	0.387	0.740	0.383-1.431	0.371	0.948	0.518-1.738	0.864	0.631	0.302-1.321	0.222
CTDS_RS*																		
Low	Ref	Ref	0.248	Ref	Ref	0.256	Ref	Ref	0.490	Ref	Ref	0.215	Ref	Ref	0.574	Ref	Ref	0.062
Moderate	1.204	0.574-2.522	0.623	1.815	0.821-4.013	0.141	1.185	0.562-2.495	0.656	1.653	0.624-4.380	0.312	1.093	0.414-2.887	0.858	0.509	0.159-1.632	0.256
High	1.445	0.922-2.264	0.108	1.392	0.878-2.206	0.160	1.302	0.839-2.019	0.239	0.813	0.469-1.408	0.459	1.296	0.780-2.152	0.317	1.454	0.826-2.560	0.1295

Adjusted for Gender, SEIFA, marital status, level of education, language spoken at home, country of birth and age. SEIFA (IRSAD): Socio Economic Index for Areas (Index for Relative Socio-Economic Advantage and Disadvantage). 974 valid responses.

\*PPSI Parenting Plus Skills Index. CTDS: Critical Thinking Disposition Scale. CTDS\_CO: Critical thinking Disposition Scale Critical Openness. CTDS\_RS: Critical Thinking Disposition Scale Reflective Scepticism. # Twitter data collected before change to X



Parents' health literacy was a significant predictor ( $p < 0.001$ ) when using social media for health information generally and before or after a health consult.

For every one-point increase in the PPSI score, parents are 21.8% less likely to use social media generally (OR 0.792; 95% CI 0.730, 0.859  $p < 0.001$ ) for health information, 22.7% less likely to use social media for health information before a health visit to a health professional (OR 0.773; 95% CI 0.713, 0.838  $p < 0.001$ ) and 27.5% less likely to use social media for health information after a visit to a health professional (OR: 0.725 95% CI 0.669, 0.786  $p < 0.001$ ).

Table 6.4 Health literacy and critical thinking impact on parents' use of social media generally, before and after health visit

	Use social media <b>generally</b> to seek health information for child			Use social media to seek health information <b>before</b> health visit			Use social media to seek health information <b>after</b> health visit		
	OR	95% CI	<i>p</i>	OR	95% CI	<i>p</i>	OR	95% CI	<i>p</i>
PPSI*	0.792	0.730-0.859	<0.001	0.773	0.713-.838	<0.001	0.725	0.669-0.786	<0.001
CTDS_ total*									
Low	Ref	Ref	0.795	Ref	Ref	0.685	Ref	Ref	0.790
Moderate	0.766	0.189-3.113	0.710	1.038	0.252-4.274	0.959	0.746	0.194-2.873	0.670
High	0.760	0.343-1.684	0.500	0.767	0.357-1.648	0.496	0.773	0.370-1.616	0.493
CTDS_CO*									
Low	Ref	Ref	0.539	Ref	Ref	0.228	Ref	Ref	0.160
Moderate	0.554	0.180-1.701	0.302	0.395	0.129-1.210	0.104	0.364	0.124-1.064	0.065
High	0.720	0.366-1.417	0.342	0.631	0.330-1.208	0.164	0.622	0.331-1.167	0.139
CTDS_RS*									
Low	Ref	Ref	0.155	Ref	Ref	0.161	Ref	Ref	0.116
Moderate	0.909	0.367-2.253	0.837	1.285	0.513-3.200	0.595	1.462	0.605-3.534	0.399
High	1.545	0.876-2.726	0.133	1.684	0.967-2.932	0.066	1.742	1.027-2.955	0.040

Adjusted for gender, SEIFA, marital status, level of education, language spoken at home, country of birth and age. SEIFA (IRSAD): Socio Economic Index for Areas (Index for Relative Socio-Economic Advantage and Disadvantage). 974 valid responses.

\*PPSI: Parenting Plus Skills Index. CTDS: Critical Thinking Disposition Scale. CTDS\_total: CTDS\_CO + CTDS\_RS. CTDS\_CO: Critical thinking Disposition Scale Critical Openness. CTDS\_RS: Critical Thinking Disposition Scale Reflective Skepticism.

## **Discussion**

More than four out of five parents of children aged between 6 months and 5 years use social media for health information for their children. Parents with higher health literacy are less likely to use social media for health information. Critical Openness was associated with Facebook and Instagram use, implying that people using these platforms may be more receptive to new ideas than parents who don't.

Our study found that parents with lower health literacy were more likely to use social media across all platforms for health information, generally, and before and after a health consult, than those with higher health literacy, leaving them vulnerable to poor-quality health information.<sup>17</sup> This result reinforces earlier studies' findings that individuals with lower health literacy may rely more on information from social media, blogs, or celebrity websites.<sup>18</sup> This relationship between lower health literacy and accessing social media for health information is concerning as parents may lack the ability to critically evaluate such information<sup>18</sup>, which can be emotive and confusing.<sup>2</sup> Australian parents may use social media to seek a second opinion or additional information or to clarify health advice.<sup>19</sup> Acting on poor quality health information can lead to delayed treatment seeking<sup>5</sup>, using non-evidence-based treatments or remedies<sup>4</sup>, or avoiding vaccines.<sup>6</sup>

Social media evolutions mean parents' health literacy needs strengthening with "technological, cognitive, social and ethical" skills<sup>20 21</sup> to minimise harms from health misinformation. There is a pressing need to understand what types of health literacy are needed for social media to promote good health.

## **Strengths and Limitations**

Possible limitations include the cross-sectional design raising the risk of responder bias, using a research company panel where participants may participate due to the incentive more than for interest in the survey topic, reliance on recall and not requesting specific social media examples. To maximise response quality, we piloted the survey on panel members.

Our study's strengths include ensuring diversity and generalisability by stratifying gender and location according to the Australian Bureau of Statistics 2016 census.<sup>11</sup> The large sample size ( $N = 1000$ ) enabled sub-group comparison.

## **Implications**

We demonstrate a parent's level of health literacy is a key determinant of their use of social media for health information, and people with lower health literacy are most likely to use social media. Parents need a better understanding of the variable quality of social media health information. Parents need better ways to check information before making child health decisions.

For clinicians, this study shows that the most vulnerable parents with lower health literacy use social media for health information, despite health advice. With this in mind, clinicians would be well placed to discuss with parents their social media use and check parents have understood the information provided to reduce their need to consult social media.

## **Conclusions**

This study has shown that parental health literacy is the most consistent factor determining if a parent of children aged 6 months to 5 years uses social media for health information, across all platforms, generally, before or after seeking professional health care for their child. This leaves those with lower health literacy vulnerable to poor-quality health information upon which to base their health decisions for their child. Research is urgently needed to scaffold parents' safe information-seeking with adequate social media health literacy skills.

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## Data availability

The datasets will not be publicly available until all publications are complete.

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## **Appendix 1 – Parents’ platform use by demographic**

### *Facebook*

Location by state ( $p = 0.021$ ) and metropolitan location within those states ( $p = 0.014$ ) were statistically significant for parents' use of Facebook for health information for their children. For location by state, the largest group was from NSW, with 64.6% ( $n = 208$ ) of all participants from NSW using Facebook for health information for their child. This was followed by Victoria ( $n = 153$ , 56.9%), Queensland ( $n = 147$ , 71.7%), South Australia ( $n = 46$ , 61.3%), Tasmania ( $n = 22$ , 75.4%), Australian Capital Territory ( $n = 7$ , 53.8%) and Northern Territory ( $n = 3$ , 75%). Most participants who used Facebook ( $n = 370$ , 61.6%) were located within a metro area.

### *YouTube*

For YouTube, significant demographic variables included parents' gender ( $p < 0.001$ ), socio-economic status ( $p = 0.009$ ), and level of education ( $p < 0.001$ ). For gender, 253 (61.3%) of male participants used YouTube for health information, followed by 272 (47.3%) of those who identified as female and seven (58.3%) of those who identified as non-binary or preferred not to disclose. For socio-economic status (as measured by the SEFIA (IRSAD)), 89.2% ( $n = 190$ ) of those in the highest quartile used YouTube compared with 96 (44.0%) of those in the second quartile, 115 (53.0%) in the third quartile, and 121 (37.1%) of those in the lowest quartile.

For education, 124 (45.4%) of the participants who had finished formal education at high school used YouTube, compared with 77 (39.9%) people with a trade and 331 (62.0%) with a university education.

### *Instagram*

For Instagram, socio-economic status ( $p = 0.004$ ), marital status ( $p = 0.009$ ), education ( $p < 0.001$ ) and country of birth ( $p = 0.005$ ) were associated with social media use for health information. For SEIFA (IRSAD), more than three quarters (75.6%;  $n = 161$ ) of participants in the highest quartile used Instagram, followed by 82 (37.6%) of those in the second quartile, 86 (39.6%) in the third quartile, and 75 (23.0%) in the lowest quartile. Sixty-eight (32.9%) of participants who were never married used Instagram, compared with 332 (44.0%) of those currently married or partnered and 13 (33.3%) of those who were separated/widowed. For education, 78 (28.6%) of those who finished their formal education at high school, 58 used Instagram, compared with (30.1%) of those with a trade and 277 (51.9%) of those with a university credential. Of those born in Australia, 42.7% ( $n = 387$ ) used Instagram.

### *Twitter*

Twitter had the highest number of significant demographic categories, with gender ( $p < 0.001$ ), socio-economic status ( $p < 0.001$ ), marital status ( $p < 0.001$ ), language spoken at home ( $p = 0.046$ ), country of birth ( $p = 0.002$ ) and age ( $p < 0.001$ ). For gender, 139

(33.7%) of the men said they used Twitter, compared with 89 (15.5%) of women and 6 (50%) of the people who identified as non-binary or chose not to disclose.

For SEIFA (IRSAD), Almost half ( $n = 104$ , 48.8%) of the people in the highest quartile used Twitter, compared with 40 (18.3%) of people in the second quartile, 39 (18.0%) in the third quartile and 41 (12.6%) in the lowest quartile for socio-economic status.

For marital status, 14.5% ( $n = 30$ ) of those who were never married/single said they used Twitter, compared with more than a quarter ( $n = 198$ , 26.3%) of those who were married or partnered, and 6 (15.4%) of those who were separated, divorced or widowed.

Twitter use was highest among university-educated ( $n = 173$ , 32.4%) followed by 38 (13.9%) people who finalised their formal education at high school, and 23 (11.9%) of those with a trade,

Almost a quarter ( $n = 229$ , 24.0%) of people whose primary language spoken at home was English said they used Twitter. Twitter use was reported by 224 (24.7%) of participants born in Australia, compared with 10 (10.6%) of those born elsewhere.

For age, Twitter use was lowest ( $n = 49$ , 15.9%) for people aged 18-19 years, compared with 23.5% ( $n = 97$ ) aged 30-39, 23.7% ( $n = 77$ ) for those aged 40-49 and 11 (24.4%) for those aged 50+.

### *LinkedIn*

Gender ( $p < 0.001$ ), marital status ( $p = 0.036$ ) and education ( $p < 0.001$ ) were significant demographics for LinkedIn use for parental health information seeking. For gender, almost a third of men (121; 29.3%) said they used LinkedIn, compared with less than 20% of women ( $n = 95$ , 16.5%) and 10% ( $n = 1$ , 8.3%) of people who identified as non-binary or chose not to disclose.

For marital status, LinkedIn use was highest amongst married people (177; 23.5%), compared with almost 20% ( $n = 6$ , 17.4%) of those who were never married or single and 4 (10.3%) of those who were separated, divorced or widowed. LinkedIn use was highest ( $n = 145$ , 27.2%) among university-educated participants, followed by 14% ( $n = 27$ ) of those who finished with a trade certificate and 5 (1.8%) of those completing formal education at high school.

### *Pinterest*

For Pinterest, significant variables were socio-economic status ( $p = 0.018$ ) and country of birth ( $p = 0.032$ ). For SEIFA (IRSAD), Pinterest use was highest ( $n = 70$ , 32.9%) among participants in the highest quartile, compared with 13.8% ( $n = 30$ ) of people in the second quartile, 12.4% ( $n = 27$ ) of those in the third quartile and 9.8% ( $n = 32$ ) of those



in the lowest quartile. For country of birth, Pinterest use was highest ( $n = 155$ , 17.1%) among people born in Australia, compared with those who were not ( $n = 8$ , 8.5%).

## 6.4 Chapter Conclusion

This chapter presented a representative cross-sectional study investigating Australian parents' health literacy and critical thinking and its impact on their use of social media for health information for their children aged 6 months to 5 years. This study found that the better that parents scored on the PPSI, the less likely they were to use social media for health information across all platforms, and generally before or after a consultation with a health professional.

This chapter answers the following research questions:

3. How do Australian parents use social media to find health information for their children and which platforms do they access?
4. Does a parent's health literacy impact their use of social media for health information for their children?
5. Does a parent's critical thinking ability impact their use of social media for health information for their children?

This study found that Australian parents that use social media use social media not only for seeking general health information but also to triangulate and fact-check information given to them by their treating healthcare professionals. They also use it to source alternative information before making health decisions for their children. Health literacy was found to be a key determinant in a parent's use of social media for health information, with a direct inverse relationship between the use of social media and health literacy as measured by the PPSI. Critical thinking wasn't found to be an overall significant determinant.

The following chapter (Chapter 7) will conclude this thesis by discussing the findings, their significance, implications, and future directions.

## Chapter 7 – Discussion

### 7.1 Introduction

The previous three results chapters presented results from investigations into different aspects of Australian parents' use of social media for health information. This included results from a representative Australian quantitative study of 1000 Australian parents of children aged 6 months to 5 years in Chapters 4 and 6, as well as a qualitative interview of 19 parents of children aged 0-18 in Chapter 5. In this chapter, we will explore the key findings, compare these with results presented in the scoping review (Chapter 2) and consider what the results of this thesis mean now and in the future. The pragmatic, mixed methods research design used in this research was used to collect and analyse both qualitative and quantitative data to research this phenomenon (Creswell & Clark, 2017). By using both qualitative and quantitative data in a mixed methods exploration of this phenomenon, both methods were synergistically strengthened together, and the weaknesses of both methods were minimised, resulting in comprehensive findings that are rigorous and sound (Creswell, 2017; Tashakkori & Teddlie, 2021).

### 7.2 Key Findings

In this thesis, there are six key findings that are particularly significant, giving new insights and offering a foundation for future research. These six findings, discussed in further detail in this chapter, are:

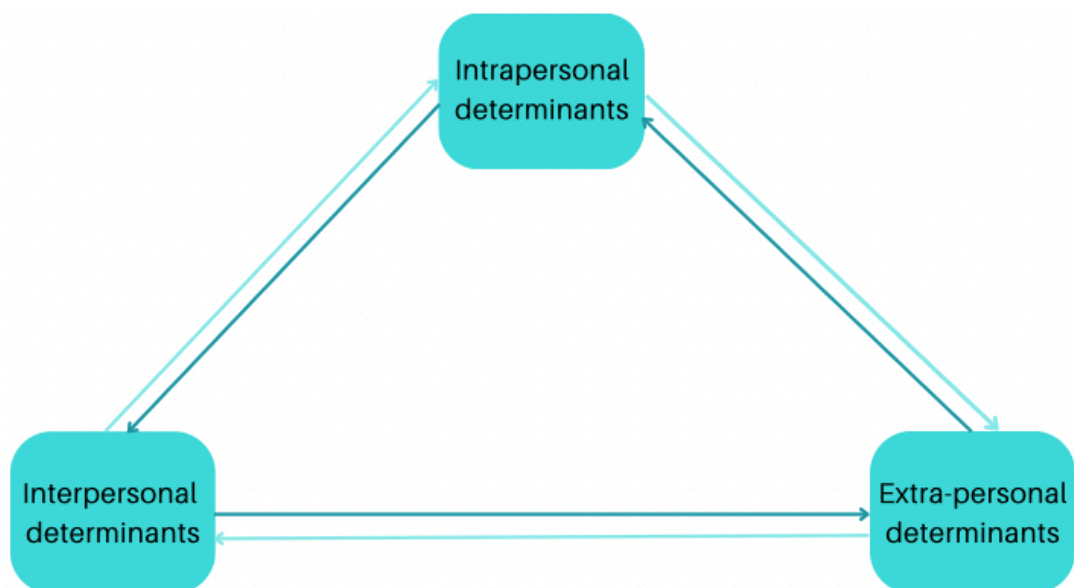
1. New knowledge of the prevalence, reasons, and motivations for Australian parents' use of social media for health information (Chapter 4)
2. Insights into parents' sense of self-efficacy and agency when they use social media for health information (Chapters 4 and 5)
3. The inadequacy of parental health literacy to face the new challenges of social media (Chapter 6)
4. The value of social media to provide health information to and support for parents by way of Virtual Villages (Chapters 4 and 5)
5. Health information on social media is vastly different to traditional health information (Chapter 5)

6. The lack of readily available, accessible evidence-based health information is driving parents to seek child health information from social media (Chapters 4, 5 and 6)

The discussion will be framed by Bandura’s Triadic Reciprocal Determinism model, with each key finding being discussed in the relevant section. Just as Bandura notes that there is a constant and dynamic influence between determinants, so too there is between key findings, which may be reflected by some degree of overlap between findings.

In keeping with Bandura’s person-first agentic perspective within this theory, but also when applying this theory to intangible space such as social media, the three corollary determinants to reflect this novel application are Intrapersonal (personal), Interpersonal (behaviour) and Extra-personal (environmental).

Figure 7.1 Triadic Reciprocal Determinism



Adapted from (Bandura, 1986, pp. 23–24; Bandura & Cervone, 2023, p. 9)

### 7.2.1 Intrapersonal determinants

Personal determinants, as defined by Bandura, are “cognitive, motivational, affective and biological events” (Bandura, 1986, pp. 23–24; Bandura & Cervone, 2023, p. 9). They are also “competencies, aspirations and values” (Bandura & Cervone, 2023, p.

10). For the purposes of this discussion, they will be referred to as ‘intrapersonal determinants’. The findings discussed in this section are: (1) prevalence, reasons & motivations, (2) self-efficacy and agency, and (3) parental health literacy skills.

#### *7.2.1.1 Prevalence, reasons, and motivations*

In the nationally representative survey of 1000 Australian parents (Frey et al., 2023) it was found that 82.8% of Australian parents use social media for health information for their children. The survey also revealed that Australian parents have many motivations for using social media for general health information, including seeking out general information about a health problem or illness of concern, to determine if medical attention is necessary, to find out about alternative treatments for the problem or illness, to seek information about possible medical treatments for the problem or illness and to seek self-management strategies (Frey et al., 2023).

Parents aged 30-39 (and 50+) who were born in Australia were most likely to use social media for health information, both before and after consultation. Those aged 30-39 sit firmly within the age group dubbed “social media natives” (Brandtzæg, 2016), i.e. those who have never known an information landscape without the internet and social media. This could explain this finding- that it follows that those who have only ever known and used social media as part of their everyday day would continue to do so when seeking health information pertaining to their children. This doctoral study has discovered parents’ reasons for using social media for health information, not just generally, but pre-and post-health consultation – one of the research’s major contributions to the literature.

#### *7.2.1.2 Self-efficacy and agency*

The qualitative arm of this doctoral study showed that parents feel that their self-efficacy, agency, and empowerment are all used by and increased by their use of social media for health information.

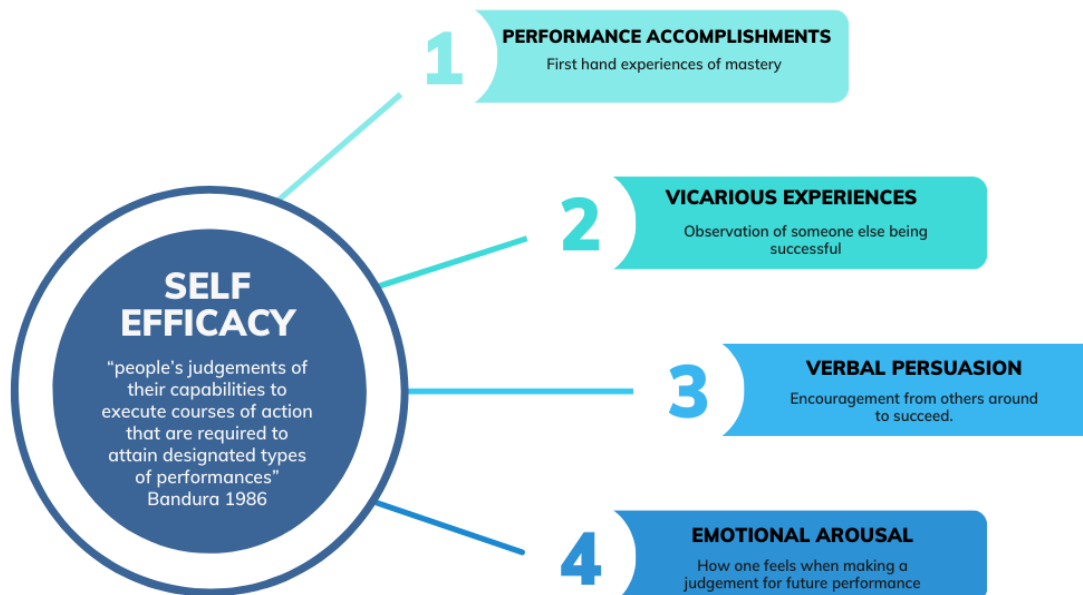
Throughout this study, self-efficacy, agency, and empowerment were themes that were in the background but always present – much like they were waiting to be noticed, identified, and brought forward.

Self-efficacy is defined as:

“people’s judgements of their capabilities to execute courses of action that are required to attain designated types of performances” (Bandura & Cervone, 2023, p. 53)

Bandura’s self-efficacy theory states that self-efficacy is foundational to a person’s agency, which results from the interplay between intrapersonal, interpersonal and extra-personal determinants as outlined in the Triadic Reciprocal Determinism model (Bandura, 1986; Bandura & Cervone, 2023, p. 53). According to Bandura, a person’s self-efficacy can be strengthened (thereby strengthening a person’s sense of agency) by four forms of information, as presented in Figure 7.2, and summarised below.

Figure 7.2 Self-Efficacy (Bandura & Cervone 2023 pp76-78)



These are explained as:

1. Performance Accomplishment: Being able to achieve a goal is the most effective way of proving to oneself that they are able to achieve that goal.

Achieving that goal through adversity also leads to resilience (Bandura & Cervone, 2023, p. 76)

2. Vicarious Experience: Modelling what success looks like for the observer and then breaking it down into 'sub-skills' that the observer can achieve is of most value when trying to master complex skills. Modelling is most successful and 'more readily builds personal beliefs among observers if those observers judge the model to be similar to themselves' (Bandura & Cervone, 2023, p. 77).
3. Verbal Persuasion: The most successful verbal persuasion occurs when the people doing the encouragement have expertise or credibility for what the individual is trying to achieve. Consensus amongst numerous credible 'encouragers' is even more effective at verbally persuading the individual. It is important to note that words lose potency and relevance when they are contradicted by evidence, which will inevitably cast doubt on the individual's self-efficacy and the encourager's credibility. (Bandura & Cervone, 2023, p. 77)
4. Emotional Arousal: Being aware of one's body state and overall emotional arousal can inform an individual of how they evaluate their self-efficacy. Physiological arousal is open to an individual's interpretation and as such, isn't of much value to an individual on its own without other information to give it context (Bandura & Cervone, 2023, pp. 77–78)

By engaging with social media in a supportive context, parents can increase their self-efficacy by learning from what is provided to them on social media. By being actively encouraged by other parents (social persuasion), seeing other parents achieve goals (vicarious experiences) and seeing how rewarding it can be (emotional arousal), parents are being channelled towards accomplishing the task themselves (performance accomplishment), all of which work towards increasing their self-efficacy (Bandura, 1986, pp. 399–409), and ultimately, their agency (Bandura, 1997, p. 3).

This finding is consistent with other research findings that have shown that being part of social media support groups improves parental self-efficacy. Previous studies have found parents to have increased levels of self-efficacy as a direct result of being part of a social media group specific to their child's health concern, resulting in feeling more educated and empowered as to how best to manage their child's condition (Clapton-

Caputo et al., 2020; Nicholl et al., 2017). In other circumstances, as parents became more self-efficacious, they were able to rely on social media less over time for recurrent caregiving situations such as self-managing hydrocephalus shunt blockages (Naftel et al., 2013).

### *7.2.1.3 Health literacy of parents*

The representative survey in Chapter 6 incorporated validated scales to test parents' health literacy (PPSI) (Ayre et al., 2020) and critical thinking (CTDS) (Sosu, 2013) with demographic and social media questions, allowing for associations to be measured. This arm of the research showed by logistic regression that parents with higher health literacy as measured by the PPSI and higher levels of education were less likely to use social media for health information. This was consistent across all social media platforms and variables, whether it was for general health information or before or after a health consultation.

It is difficult to find a single catch-all definition of health literacy. This is due in part to the direct influence of social media's rapid and continuing evolution, which sees the landscape shift with every update. As users respond to (boyd & Ellison, 2007), and (re)integrate these changes and developments into their everyday lives (boyd & Ellison, 2007; Ellison & boyd, 2013; Van Dijck, 2013), the context that they are responding within also changes. To date, however, there has been little recognition of the convergence of health literacy with the challenges of social media.

Health literacy is defined as:

“...represent(ing) the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health”. (Nutbeam, 2000)

A parent's health literacy has been shown to have a direct impact on a child's health and well-being, for example, with teeth brushing, nutrition and exercise (de Buhr & Tannen, 2020). Parental health literacy has also been found to be vital for children with chronic conditions (Zaidman et al., 2019) and those with medical complexity

(Lawrence et al., 2021), and chronic and remitting conditions such as asthma (DeWalt & Hink, 2009). Parental health literacy has also been shown to be a determinant of how a parent uses and navigates the health system (Choudhry et al., 2019).

Nutbeam and colleagues define basic health literacy as the cognitive and social skills that determine the motivation and ability of individuals “to acquire, understand and use information in ways which promote and maintain good health” (Institute of Medicine, 2004; Nutbeam, 1998), and that “Health literacy means more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment.” (Nutbeam, 2000 p. 264)

However, in practice, health literacy has developed to encompass much more than being able “to read pamphlets and successfully make appointments” (Nutbeam, 2008 p.2075. By improving people's access and capacity to evaluate health information critically, health literacy is vital to the empowerment (Zimmerman, 1995) and self-efficacy that results from that empowerment (i.e. agency).

Nutbeam’s Critical Health Literacy model (Nutbeam, 2000) has three levels. The bottom level is basic or functional health literacy, where the person is able to read and write sufficiently on a day-to-day basis. This is followed by communicative/ interactive health literacy, which requires more advanced cognitive and literacy skills than basic health literacy. However, the person is more adaptable to the demands of meeting their health literacy needs, being able “to actively participate in activities, extract information and derive meaning from different forms of communication and to apply new information to changing circumstances.” (Nutbeam, 2000, pp. 263–264)

The most advanced level of Nutbeam’s model is that of critical health literacy itself. Critical Health Literacy requires “more advanced cognitive skills, which, together with social skills, can be applied to critically analyse information and to use this to exert greater control over life events and situations” (Nutbeam, 2000, p. 264) i.e. using one’s self-efficacy to exercise agency. While Nutbeam’s definition is true of the skills that individuals need to understand health information, it does not consider the context or environment of the information exchange and the challenges that different



environments and interactions pose to the user and their interaction with the information. Rather, critical health literacy “can be seen as a concept made up of interconnected domains which relate to other important constructs, but which nevertheless retains a key focus on the interaction between individuals and information about health” (Chinn, 2011, p. 65).

With the increasing use of social media for health information, the definition of health literacy needs to acknowledge the user’s ability to access, understand and integrate information to make health decisions, but also the challenges of navigating the social media environment. Additionally, Bandura’s Triadic Reciprocal Determinism model shows the dynamic influence that the person, information, and environment (i.e. social media) have on each other also, which comes to the fore when using social media for health information seeking. It is from this perspective that Wharf, Higgins and Begoray posit that critical health literacy needs to account for media’s influence in the interaction between the user and the health information, recognising that media literacy is a crucial element of health literacy when using media (Wharf Higgins & Begoray, 2012). From this, they have developed a new model of health literacy, melding health literacy and media literacy together to forge this definition:

“(C)ritical media health literacy is a right of citizenship and empowers individuals and groups in a risky consumer society to critically interpret and use media as a means to engage in decision-making processes and dialogues; exert control over their health and everyday events, and make healthy changes for themselves and their communities” (Wharf Higgins & Begoray, 2012 p.142).

Along with the actual health information exchanged, the social media environment and its variables contribute significantly to how information is received and used by the user (Grover et al., 2022). When considering health literacy and social media, being able to navigate social media platforms and their idiosyncrasies and nuances is as important as being able to read and understand the information presented (Polanco-Levicán & Salvo-Garrido, 2022). Indeed, health literacy plays a major role in how parents discern health misinformation on social media. Higher levels of health literacy has been found to be associated with those that are better at discerning credibility in

regard to health misinformation (Song et al., 2019) and that they were less likely to share or circulate misinformation on social media (Oh & Lee, 2019).

Studies have shown that parents do not have certain or consistent ways of determining the quality of the health information that they find on social media. Methods that have been reported to be used by parents include translating information into their native language on Google Translate (Gorman et al., 2019), assessing how the information was presented aesthetically (Thorpe et al., 2020), and self-styled triangulation by crowd-sourcing consensus (Criss et al., 2015; Gage-Bouchard et al., 2019; Moon et al., 2019; Thorpe et al., 2020). Other methods mentioned included being guided by inner wisdom, gut feeling, and intuition (Price et al., 2018).

When asked how parents evaluate or determine what information to trust in the doctoral research studies, Australian parents spoke of trusting the experience of other parents in their social media groups, especially if the same issues were being experienced repeatedly. Others spoke of trusting parents who had a lot of experience with the illness (Clapton-Caputo et al., 2020; Naftel et al., 2013), elevating them and their knowledge above that of their treating team in some cases.

This doctoral research's results are not inconsistent with previous studies that have shown that parents trust information found on social media from other parents because they believe the information found to be detailed, customised, and relevant to them and their situation (Garcia et al., 2019; Lupton, 2016); unbiased, inherently trustworthy (Sharpe et al., 2016) because it comes from other parents and from a personal perspective, and it provides insights based on lived experience (Lebron et al., 2020) that a health professional wouldn't necessarily be able to provide (Gage-Bouchard et al., 2019). In another study, it was found that online crowd wisdom is viewed by parents as equally or more credible than the advice of healthcare professionals (Bäckström et al., 2017). However, parents have also stated that they can find the information found on social media to be confusing (Bradshaw et al., 2020) due to the complexity of the language used and the information presented (Thorpe et al.,

2020). Parents, however, have also stated that they experienced overwhelm (Price et al., 2018) as a result of seeking health information on social media.

### 7.2.2 Interpersonal determinants

Interpersonal determinants include behaviour, as Bandura originally postulated (Bandura, 1986, p. 24), but have been expanded to include interpersonal communication and interaction as found on social media. They are the way that people interact with each other despite not being face-to-face but rather screen-to-screen. The findings discussed in this section are (1) 'Virtual Villages' and (2) like-minded people.

#### 7.2.2.1 *Virtual villages*

A strong theme through both the qualitative and quantitative arms of this doctoral research was that of community (Frey et al., 2023; Frey, Bonfiglioli, & Frawley, 2024; Frey, Bonfiglioli, Muscat, et al., 2024). It was found that one of the main reasons parents use social media for health information for their children is not only for information but also for support and a sense of community. This was one of the stronger themes across both the quantitative and qualitative data with 77% of parents agreeing that is one of the reasons they use social media for health information in the representative study.

The scoping review in Chapter 2 (Frey et al., 2022) showed that there were many positive benefits that parents saw in using social media for information, as evidenced by the studies analysed in the review which included: being a safe and private place to discuss sensitive issues (Baker & Yang, 2018; Clapton-Caputo et al., 2020), obtaining support (Baker & Yang, 2018; Castro et al., 2019; Clapton-Caputo et al., 2020; Criss et al., 2015; Gage-Bouchard et al., 2019; Moon et al., 2019; Zhao et al., 2019), gaining reassurance/validation for decisions already made (Price et al., 2018), and receiving information from other parents based on their lived experience (Bryan et al., 2020; Gage-Bouchard et al., 2019; Garcia et al., 2019; Kulhas Celik et al., 2019; Lebron et al., 2020; Mohd Roffeei et al., 2015; Moon et al., 2019; Naftel et al., 2013; Pretorius et al., 2019; Price et al., 2018; Rehman et al., 2018; Sharpe et al., 2016; Wang & Lund, 2020;

Zhao et al., 2019). Post-diagnosis, parents reported feeling more educated about their child's condition as a result of using social media (Nicholl et al., 2017) and more informed and self-efficacious (Bandura & Cervone, 2023) as to how best to manage their child's condition (Clapton-Caputo et al., 2020; Nicholl et al., 2017).

Just as in real-life communities where there are benefits and challenges, there are both positive and negative aspects of social media's ability to facilitate social support. Examples of social media's specific benefits include its ability to overcome barriers that can be problematic for parents in real life, such as geographical (Frey et al., 2022) and logistical (Kaplan & Haenlein, 2010; Kim et al., 2016) barriers, and as such, parents are able to engage where it might not have been possible without social media (Picard, 2015).

However, social media isn't the panacea to modern health information seeking. Examples of negative aspects of social media include information quality concerns (Bryan et al., 2020; Gorman et al., 2019; Kim & Hawkins, 2020; Koskan et al., 2019; Walker et al., 2017), privacy concerns (Criss et al., 2015) and unhelpful group dynamics culminating with parents feeling misled (Hwang & Shah, 2019; Jenkins & Moreno, 2020), as well as being witness or involved in conflict (Deas et al., 2019), leading to anxiety (Nicholl et al., 2017). Interpersonal impacts from social media interactions can also make using social media challenging (Price et al., 2018), including anti-social behaviour such as trolling (Bradshaw et al., 2020), dogpiling, brigading and doxing. Recent studies have shown that this behaviour can be the result of the perpetrator wanting group acceptance and social approval (Soares et al., 2023), amongst many other reasons, including boredom and revenge (Owen et al., 2017, p. 127).

Despite these challenges, social media has increasingly been used by parents to seek health information and support (Bryan et al., 2020). For support, parents use social media to find like-minded people with lived experience. A 2011 study (Cowie et al., 2011) highlighted that support can be a major, if not the predominant, motivator for member interaction on social media. Cowie conducted a content analysis of a breastfeeding support forum, which found that 96.8% of member comments were in

support of each other, followed by 29.1% of comments giving information, 17.1% seeking support and 7.7% seeking information.

#### *7.2.2.2 Like-minded people*

Social media has enabled the facilitation of connections with like-minded people that may not have been possible previously due to various logistical and geographical barriers (Dwivedi et al., 2018; Picard, 2015). Seeking out like-minded people (also known as homophily) has been found to be hard-wired into people, especially for things that matter most to them (Bahns et al., 2017), such as parents would when discussing their children's health. This leads to groups where members are comfortable and trust each other, allowing for cooperation for goals to be achieved and often successful (Crandall & Brahns, 2016). Indeed, it is the similarity between group members that allows this environment to be created, and is particularly useful for success (Crandall & Brahns, 2016). A 2019 study found that parents thought the other parents in their social media groups to be more educated than their treating health professionals when it came to self-management and caregiving strategies for their children (Gage-Bouchard et al., 2019), whilst other parents stated that they trusted other parents on their social media groups than their treating health professionals (Sharpe et al., 2016). Within the groups, members who were more experienced with the condition were trusted more than newer members (Clapton-Caputo et al., 2020; Naftel et al., 2013). These members were also viewed as being authorities within the confines of their very specific niche of lived expertise.

Social connection, whether in real life or online, is important for physical and mental benefits (Wilkinson et al., 2019). However, not all aspects of groups of like-minded people on social media are positive or beneficial to a person's (or their child's) health. Group dynamics can lead to a 'them and us' group mentality, where social media tends to bring together like-minded people into cliques with shared identities, which can have a significant influence on each other (Sirola et al., 2021). When this happens, it becomes increasingly difficult for different or dissenting voices to be heard and valued, leading to what are commonly referred to as 'echo chambers' (Hall Jamieson & Cappella, 2010). Echo chambers are when only the dominant messaging from the group is echoed over and over to the exclusion of all other information (Hall Jamieson

& Cappella, 2010) and are often the catalyst for misinformation (Del Vicario et al., 2016). This, in turn, leads parents to more polarising information and the perception that they have found the singular truth for their enquiry (also known as the confirmation bias (Lorenz-Spreen et al., 2020; Sunstein, 1999)). A study published in 2022 looking at German anti-vax social media found that homophily (i.e. like-mindedness) together with a person's processing of information (i.e. confirmation bias) leads to social influence by way of reinforcement (Müller et al., 2022). Social influence by way of reinforcement was also found to be the case in a thematic analysis of a closed Facebook group for vaccine-hesitant parents (Bradshaw et al., 2020), where it was shown that parents can go from being ambivalent to decidedly anti-vax within a single interaction within a closed group that functions like an echo chamber. The issue with this for parents, however, is that as these groups are echo chambers where dissenting or differing perspectives are not tolerated, which means that parents are making decisions based on only seeing one (and at times, extreme) perspective, possibly based on (a negative or rare) lived experience of a single person or small group of people instead of the evidence gathered from populations.

Storytelling has always been known to be a really effective way to communicate to and through generations- it has been used by cultures for millennia (Picard, 2015), including the Australian First Nations people, as a primary method of communication throughout their history (Watarrka Foundation, 2024), but also as a way to deepen connections within their community. In much the same way, narratives and storytelling in Facebook groups have been shown to have the same impact (Hou, 2023). It is through storytelling that parents can be influenced most on social media as it lends a sense of intimacy to the group, where stories of personal struggles and difficulties are laid bare for the group to see, digest and, in some instances, lend support – all deepening a sense of community amongst the members of the group (Hou, 2023). Stories and narratives are able to capture an audience's attention and imagination while relaying information that is designed to persuade the audience (Jones & Anderson Crow, 2017). It is also through stories and narratives that misinformation spreads best on social media (Hamby et al., 2024). The result is that parents using social media for health information are exposed to the misinformation contained within the stories and narratives that are spread on social media, being

susceptible to influential messages (Picard, 2015), impacting their ability to make appropriate health decisions for their children (Betsch et al., 2012) and potentially leading to suboptimal health outcomes for the child.

### 7.2.3 Extra-personal determinants

Extra-personal determinants are what Bandura called ‘environments’ (Bandura, 1986, pp. 23–24). To be more inclusive of social media, being in virtual spaces, extra-personal determinants can be anything that impacts a person’s use of social media that is external to them and beyond their control. Determinants in this category included the differences between health information from social media versus traditional health information and the lack of easily available accessible evidence-based health information. This section will discuss (1) the difference between social media and other forms of media and (2) the lack of readily available evidence-based health information.

#### 7.2.3.1 *Difference between social media and traditional health information*

The definition of social media has long evaded consensus. Reasons for this include the fast pace at which platforms evolve, develop and provide functions and services (boyd & Ellison, 2007) and how quickly those functions and services are integrated into everyday life (Lee et al., 2014; Price et al., 2018). The definition best suited to this research, and with wide acceptance, is:

“a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0 and that allow the creation and exchange of user-generated content” (Kaplan & Haenlein, 2010, p. 61).

This definition captures the functions that have positioned social media as a leading information resource. Not only do the platforms act as enduring repositories for information generated by users, but they also allow users to retrieve and exchange information between the platform and the Internet (Web 1.0) seamlessly and interchangeably (Van Dijck, 2013, p. 4).

The early promise of Web 2.0 was that it would “liberate content”, with the free tools to create content available to amateurs and the more experienced (web) citizens alike,

releasing the creation of content from the restrictions of the past ownership and power structures of the mass media (Van Dijck, 2013, pp. 160–161). With more people creating content, there would also be a marked increase in the diversity of content being circulated (Van Dijck, 2013, pp. 160–161), altogether resulting in a democratisation of knowledge and information, only made possible by the advent of Web 2.0 (Picard, 2015). And it did. But not how it was expected.

User-generated content (UGC) is the lifeblood of the social media (Van Dijck, 2013, p. 35). From the user's perspective, platforms facilitate space for people "to support (the) exchange ideas and information and create and facilitate communities" and to "discuss and debate, to share information from storehouses of knowledge, and to exchange ordinary and banal information" (Picard, 2015, p. 34), portrayed as some as being the definition of "an empowering force" and a marked departure from the mass media before it that was steeped in process and formality, limiting who could speak and be heard (Picard, 2015, p. 35).

However, with UGC came the introduction of irregularity and unpredictability as far as what information will be generated and circulated on social media. Without the formal gatekeeping and editorial processes that made mass media production burdensome but reliable (Singer, 2014), information isn't quality-controlled before it is released into the world for everyone to see. As social media became corporatised, the quality of content became somewhat irrelevant as all the financial streams of the business of social media relied on the quantity of content instead of the quality (Van Dijck, 2013, p. 161). This has resulted in swathes of easily accessible low-quality information and misinformation circulating amongst high-quality information, with parents commonly unable to discern those that are evidence-based and relevant to them.

Associated with the original utopian vision for social media along with social media's capacity for UGC, communities can produce their own information and disseminate it on social media (Bradshaw et al., 2020). Mostly, this is harmless, but at times, it can be particularly harmful. One example of this can be seen in the rapid growth and reach of the anti-vax movement. (Bradshaw et al., 2020; Kata, 2010). The impact of the anti-vax movement is so great that the World Health Organisation declared vaccine hesitancy



as one of the top 10 threats to global health in 2019 (World Health Organization, 2019). In the United States, for example, measles was declared eliminated in 2000 (CDC, 2023). Yet, there have been significant cluster outbreaks of measles since, including in 2015, when 188 people contracted measles after a visit to Disneyland (Oldstone, 2024). The majority of those who contracted measles from that exposure were either under-vaccinated or unvaccinated by choice, while 12 children were too young to have received the vaccination schedule for full protection (CDC, 2015).

#### *7.2.3.2 Lack of readily accessible evidence-based health information*

Lack of access to objective, evidence-based information is not an issue that is exclusive to social media or even the Internet; it is an overarching and significant barrier to scientific and evidence-based information and knowledge in general. 'Information Poverty' results from the withholding of information from those to whom it is relevant by secrecy (lack of transparency and intentional exclusivity), deception (information not being disseminated to all stakeholders, despite their relevant need) and hindrance, which is the result of stakeholders not being able to access information despite it being relevant to them (Chatman, 1996). This lens brings an interesting perspective to the way that social media and the wider informational landscape interact and converge – where demand for evidence-based information is not driven by those who are privileged to have unfettered access to it but increasingly from those who require it and have not previously been privy to it. Information poverty is epitomised by parents seeking out evidence-based information and are left with only abstracts to inform their health decisions (Frey, 2019; Koopman, 1997), as the relevant evidence-based health information article they require is generally sequestered behind paywalls. Where traditionally, parents might have approached a healthcare professional who was able to access the health information needed that was widely inaccessible, they are now increasingly seeking information independently, due in part to social media's democratisation of information (Van Dijck, 2013, p. 161).

The lack of accessible evidence-based information is a persistent and unremitting problem, which has often been the impetus for parents to use social media for health information. To be accessible, information needs to not only exist but to also be able to be read, understood, and used (either by way of consideration or to be acted on).

Evidence-based health information has traditionally been targeted towards very specific audiences – clinicians and researchers, namely – who have extensive and specialised knowledge at the level that research conventionally is published, making it inaccessible to those without the same knowledge and educational background. The same information is also often sequestered behind paywalls, making it physically and financially inaccessible to many Australians. For information to be equitably accessible, it needs to be translated and presented at a level that most Australian parents can understand and found in places where most Australians can access it. This would mean simplifying information to read at a Year 7 (12-13 year old) level (Australian Government, 2024) and making the information widely and easily available.

Not being able to access information and understand it is disempowering (Australian Council for Educational Research, 2021). Low health literacy in adulthood can result from many different circumstances, including cultural, language, education and adverse childhood experiences (Ferguson, 2021). However, research shows that adults from multicultural and disadvantaged backgrounds have poorer outcomes and higher rates of hospitalisation compared with adults without disadvantage (Khatri & Assefa, 2022). Health literacy is also a stronger predictor of health outcomes than income, education, employment status, race or age (Shahid et al., 2022).

Research has found that simplified evidence based resources benefit everyone, not just those identified as needing more accessible information (Stableford & Mettger, 2007). Accessible health information improves patient understanding, saves time and money and improves overall patient satisfaction (Stableford & Mettger, 2007). However, accessible health information continues to be hard to find, leading many to seek information from alternative sources, including social media.

## 7.3 Implications

### 7.3.1.1 *Individual implications*

Parents and their use of social media for health information were the focus of this research. However, the implications of social media use for health information are felt

most acutely by children as they are reliant on their parents to make informed health decisions and to consent to treatment on their behalf (Lee et al., 2020).

Our findings show that parents with low health literacy are more likely to use social media for health information than those with higher health literacy. Children of parents with lower health literacy are more likely to have poorer health outcomes, including medication errors at home, not having healthcare needs met and more emergency visits (Sanders et al., 2009). Children are also more likely to miss more days of school due to their chronic illness than those whose parents have higher health literacy (DeWalt et al., 2007), as well as have worse developmental outcomes with a higher incidence of depressive and withdrawal behaviours (Zaslow et al., 2001), all of which can have lifelong impacts on children.

Parents are now able to access large amounts of health information from a diversity of perspectives. However, not all information is easily identified, of high quality or relevant to parents' concerns. For example, research has shown that parents can be persuaded by how information is presented rather than the quality of the information (Zhang et al., 2022). Misinformation is an ever-present risk, with features of misinformation on social media having been found to include "a lack of meta-information, exaggerated facts, claims of unique or secret information, incomplete information, unidentified sources" (Zhang et al., 2022, p. 1395), leading the information to present with fake authority and inciting emotions. This can lead to parents enacting health information that ultimately can harm their child in a number of ways, including the abstinence from evidence-based medical care (Bradshaw et al., 2020), the use of alternative forms of therapies that can either potentially exacerbate the condition or do nothing to help the condition (Heineman et al., 2021), which can lead to delayed appropriate health care (Benetoli et al., 2018), and a more resource-intensive and longer treatment and recovery.

As a result, it is of primary public health concern that further research is undertaken to understand how best to serve parents and address their challenges of using social media for health information, including how to identify misinformation. Increasing parental health literacy will not only build parents' confidence and self-efficacy when

making health decisions for their children, but it will also improve their children's start to life.

### *7.3.1.2 Clinical implications*

The primary message from this doctoral research for clinicians is that many Australian parents are using social media to seek and discuss health information at various points in their child's health journey.

Parents' use of social media has been shown to be an influential factor in the parent/patient–HCP dyad (Asayesh & Sadeghzadeh, 2020). As social media has democratised information and knowledge, it has empowered parents by enabling them to access information that was previously unavailable to them (Van Dijck, 2013, p. 161). In some cases, this has strengthened the dyad, but in others, it has introduced uncertainty into the therapeutic relationship. While for some parents, being transparent about the information they have found on social media has enabled them to work more as a team with their HCPs (Ferguson & Candib, 2002); however, other research has found that parents can be encouraged by others on social media to intentionally withhold information relevant to a HCP's care of their child when seeking care (Bradshaw et al., 2020) for example to avoid judgement or being lectured about the harms of non-vaccination of their children (Bradshaw et al., 2020). This is not only potentially wasteful of an HCP's time and resources, but it also adds strain to the therapeutic dyad (Stukus, 2019) and introduces unknown risks to both the HCP's clinical judgement and, by extension, the health outcomes for the child.

Clinicians could consider routinely asking parents about their use of social media for their child's health. This could encourage open dialogue about information found on social media, and ultimately builds trust (Karras et al., 2019). Clinicians could also potentially have a small list of social media content that is evidence-based that they could readily recommend to parents to access, leaning into social media's ability to present information in varying formats (Frey et al., 2023) accommodating for varying literacy needs.

### 7.3.1.3 *Public health implications*

Multiple factors, including the lack of social media regulation, the impacts of peer influence, and low health literacy for many parents, create a troubling situation for public health. The speed at which misinformation spreads and its impact (Stukus, 2019) has been evidenced by the increase in vaccine-hesitancy in some countries (Vaccine Confidence Project, n.d.) and the more recent reluctance by some individuals and communities to comply with COVID-19 public health measures (Kearney et al., 2024).

Several recommendations could help to address the issues that have been discussed. Firstly, health systems could evaluate how they support parents with sick children, especially those with chronic or orphan illnesses, in practical and informational ways. Our research found that it is often the lack of practical caregiving and logistical information at the time of diagnosis that leads parents to use social media to understand more holistically the needs of their sick child (Frey et al., 2023). To have the health system proactively meet this need, with a variety of strategies (Clark et al., 2011), would help stem parents' need for social media for health information, at least initially. Ideally, this would entail the creation of accessible, evidence-based health resources to address parent's information needs, co designed with parents ensuring that the knowledge translation is into formats most relevant to their needs (Hartling et al. 2024a), such as the pioneering work in this space in Canada. Ensuring that parents can access information at the time of diagnosis and understand it by having resources that are tailored to their level of health literacy (i.e. resources written at a Year 7 level for the average Australian adult and Easy English for those that require formats that are easier to read (Australian Government, 2024)) will make significant in-roads to ensuring that evidence-based information is in the mix when parents make their health decisions for their children (Hartling et al, 2024b).

Secondly, educating parents about what misinformation looks like by 'pre-bunking' has been shown to dramatically lower the impact of misinformation on social media, as parents would be 'inoculated' and forewarned as to what misinformation looks like (Lewandowsky & van der Linden, 2021). Pre-bunking, grounded in inoculation theory, is based on the premise that resistance to misinformation and misleading persuasion

can be built by two core components- firstly, fore-warning and education about common misinformation, followed by a micro-dosing of weakened misinformation and the evidence-based stance on the misinformation to refute it as well as possible misleading arguments or persuasion techniques that might be encountered (Roozenbeek et al., 2022). By educating parents about the features of misinformation found on social media, parents would not only be able to protect themselves and their children better, but also the communities that they are part of. This could be integrated into patient counselling, but also resources that they can take home with them, online resources or formal or informal support groups.

Finally, whilst parents remain vulnerable to influence (Stanton & Guion, 2013) and misinformation on social media, particularly by way of narratives and stories that evoke emotions, this same strategy could be employed to present evidence-based information. Rather than continuing to use the Knowledge Deficit Model to communicate science in a repetitive and emotionless way (Jones & Anderson Crow, 2017), researchers and scientists could use traditional storytelling methods to capture parents' attention and imagination, and influence with science and evidence-based information. One example of this strategy in action has been seen with Aboriginal and Torres Strait Islander communities in Australia, with visual storytelling being used by Diabetes Australia to raise awareness and spread evidence-based information about Diabetes (Diabetes Australia, 2020). Using beautiful artwork illustrated by an indigenous artist, leaning into the aspects of life that are culturally most important, Diabetes Australia has been able to effectively highlight the importance of diabetes diagnosis and management to the Aboriginal and Torres Strait Islander community, as it impacts not only what is important in the individual's life but that of their community too.

#### 7.4 Future Directions

The research conducted in this thesis has been timely and well-received, showing a paucity of research in the area, with scope for further research in the future.

As this research is broad and high-level, future research could focus on any number of specific parenting or child demographics and their specific use of social media for health information. This has started with 65 peer-reviewed journal articles (at the time of writing) citing the scoping review in this thesis as a general introduction to the research area. The ubiquity of social media and the depth and breadth of health and its impacts means there is fertile ground for future research to explore a more nuanced understanding of the strengths and limitations of social media use for parent health information seeking and child health information.

One key aspect of research that could not be included in the scope of this research that is vitally important to inform clinical practice and health policy would be to investigate the outcome of parents' use of health information from social media for their children. This would include parents' decisions (including their decision-making process), children's health service use, children's health outcomes and the subsequent impacts on the child, their family unit, clinical encounters and the wider health system. Being able to quantify these implications would enable estimations of the financial cost of parent's use social media for health information for the Australian health system as well as personal physical, mental and emotional costs to the child and parent. This could inform policy and future investment into further research to underpin evidence-based methods to prevent or limit the negative impacts of the use of social media for health information.

This thesis also found many positive benefits of parent's use of social media, including community and health information based on lived experience that wouldn't have been available to parents in most other circumstances. For some parents, social media provides support and strength that enables them to advocate for their child's care with their treating teams. For others it can be much simpler, with information being provided about how best to access the health services they need or for optimisation of their caregiving for their child with tips and tricks passed on by other parents. Knowing that parents have their own reasons for using social media for health information, future research could consider how best to harness the benefits felt and described by parents to best serve them and their health information needs on social media in the future.

## 7.5 Limitations

This doctoral research has several limitations. Firstly, data were collected during Sydney's second COVID-19 lockdown, which required adapting what was standard up until that point (for example, face-to-face interviews) with what was legally compliant (Zoom, 2021) This accommodation, however, had advantages, as it allowed us to collect interview data from parents across Australia rather than Greater Sydney as had originally been planned.

Originally, the research was planned to be an explanatory sequential design (Creswell & Plano Clark, 2018, p. 65) using the interviews to inform the survey to understand how widespread the common experience would have been explored in the interviews. However, to comply with the legislated and practical COVID-19 restrictions at the time of data collection, the research plan had to be altered, resulting in a parallel-database convergent research design (Creswell & Plano Clark, 2018, p. 73), where only the scoping review was able to inform the survey and interviews.

The qualitative research component of this research may have been strengthened by the inclusion of a targeted more diverse sample of parents to represent the Australian population and modern parenting experience- for example, more fathers, disabled parents, and broader multicultural (especially non-English speaking background) representation. To do this would have required significantly more resources and time, but it would serve the evidence base well if it were to be included in future research.

## 7.6 Chapter Summary

Chapter 7 outlined the key discussion points from this research, namely Australian parents' motivations for using social media for health information, their insights into self-efficacy and agency as a result of using social media, the inadequacy of parental health literacy to face the challenges of social media, the value of social media for health information and support for parents, information on social media is vastly different to traditional health information, and the lack of available and accessible



traditional health information is driving parents to seek health information from social media. Future research areas were also identified, and limitations discussed.

## 7.7 Conclusion

This research examined the use of social media by Australian parents for health information for their children and identified a number of significant findings that were not known previously.

### **Finding 1:**

The typical Australian parent who uses social media is aged between 30 and 39 years and born in Australia.

### **Finding 2:**

Australian parents use social media for health information for their children to seek emotional and informational support from other parents who are like-minded or who share lived experiences of the same health journey for their children. Information shared can include caregiving tips and advice, as well as in-depth information about the specific condition or illness that the children share, as well as navigating the health system and condition-specific health information.

### **Finding 3:**

A significant proportion of Australian parents use social media for health information for their children generally such as for information about general health and wellbeing for their child (82.2%). Australian parents use social media for health information before seeing a healthcare professional to understand the possible issues at hand but also to feel more confident in their interactions with the healthcare professional. Post consultation, Australian parents use social media to reassure themselves and to seek out further information before making health decisions for their children.

### **Finding 4:**

Australian parent's level of health literacy is the key determinant for the use of social media to seek information about their child's health. Parents with higher health

literacy were less likely to use social media for health information across all platforms and circumstances. A parent's critical thinking had little impact.

This doctoral research contributed to the field of public health by investigating the determinants, drivers, and characteristics of Australian parents who use social media for health information for their children. This thesis also outlines future research opportunities to build upon the findings from this research and develop a further understanding of this essential emerging research area.

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## Appendices

### Appendix A – PRISMA-ScR Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
<b>TITLE</b>			
Title	1	Identify the report as a scoping review.	Completed
<b>ABSTRACT</b>			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	Completed
<b>INTRODUCTION</b>			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	Completed
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	Completed
<b>METHODS</b>			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	Not applicable
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	Completed- Table 1
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional	Completed

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
		sources), as well as the date the most recent search was executed.	
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Completed – Table 2
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	Completed
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	Covidence
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	Completed
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	Not applicable
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	Completed
<b>RESULTS</b>			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	Completed
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	Completed - Table 3
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	Not applicable

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Completed
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	Completed
<b>DISCUSSION</b>			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	Completed
Limitations	20	Discuss the limitations of the scoping review process.	Completed
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	Completed
<b>FUNDING</b>			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	Completed

## Appendix B – STROBE Statement - Checklist

STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation	Page No
<b>Title and abstract</b>	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	1
<b>Introduction</b>			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	2
Objectives	3	State specific objectives, including any prespecified hypotheses	2
<b>Methods</b>			
Study design	4	Present key elements of study design early in the paper	3
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	3
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants	3
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	3
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	3
Bias	9	Describe any efforts to address potential sources of bias	3
Study size	10	Explain how the study size was arrived at	3
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	4
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	4



		(b) Describe any methods used to examine subgroups and interactions	4
		(c) Explain how missing data were addressed	3+4
		(d) If applicable, describe analytical methods taking account of sampling strategy	-
		(e) Describe any sensitivity analyses	-
<b>Results</b>			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	4
		(b) Give reasons for non-participation at each stage	-
		(c) Consider use of a flow diagram	-
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	4-6
		(b) Indicate number of participants with missing data for each variable of interest	3
Outcome data	15*	Report numbers of outcome events or summary measures	-
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	8,9, 11,14
		(b) Report category boundaries when continuous variables were categorized	-
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	-
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	4,7, 10,12
<b>Discussion</b>			
Key results	18	Summarise key results with reference to study objectives	15
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	15
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of	15

		analyses, results from similar studies, and other relevant evidence	
Generalisability	21	Discuss the generalisability (external validity) of the study results	16
<b>Other information</b>			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	16

\*Give information separately for exposed and unexposed groups.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at [www.strobe-statement.org](http://www.strobe-statement.org).

## Appendix C – STROBE vs CROSS Checklists

### STROBE vs CROSS

Criteria	STROBE	CROSS	Page number of report
<p><b>Title</b></p> <p>STROBE: indicate study design in title</p> <p>CROSS: include 'survey' in title</p>	1a	1a	1
<p><b>Abstract</b></p> <p>STROBE: Provide in abstract an informed and balanced summary of what was done and found</p> <p>CROSS: Provide an informative summary in the abstract, covering the background, objectives, methods, findings/results, interpretations/discussions, and conclusions</p>	1b	1b	1
<p><b>Introduction</b></p> <p>Background and Rationale</p> <p>STROBE: Explain the scientific background and rationale for the investigation being reported</p> <p>CROSS: Provide a background about the rationale of study what has previously been done, and why this survey is needed</p>	2	2	2
<p><b>Objectives</b></p> <p>STROBE: State specific objectives, including any prespecified hypotheses.</p> <p>CROSS: Identify specific purposes, aims, goals, or objectives of the study</p>	3	3	3
<p><b>Methods</b></p> <p>Study design</p> <p>STROBE: Present key elements of study design early in the paper</p> <p>CROSS: Specify the study design in the "methods" section with a commonly used term (e.g. Longitudinal, cross-sectional).</p>	4	4	3
<p><b>Setting/ Survey administration</b></p> <p>STROBE: Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection</p> <p>CROSS: Provide information on modes of questionnaire administration, including the types and number of contacts, the</p>	5	7a	3

location where the survey was conducted, (e.g. in waiting room, online using SurveyMonkey etc.)			
Data collection and methods STROBE: For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group CROSS: Describe the questionnaire (e.g. number of sections, number of questions, and names of instruments used)	8	5a	3
STROBE: For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group CROSS: Describe the questionnaire instruments that were used in the survey to measure particular concepts. Report targeted population, reported validity and reliability information, scoring and classification procedure, and reference links (if any).	8	5b	3
STROBE: - CROSS: Provide information on pretesting of the questionnaire, if performed (in the article or in an online supplement). Report the methods of pretesting, number of times the questionnaire was pretested, number and demographics of participants used for pretesting, and the level of similarity of demographics between pre-testing participants and sample population. STROBE: - CROSS: Questionnaire, if possible, should be fully provided (in article, as appendices or as an online supplement)	Not included	5c	3
	Not included	5d	Not applicable
Sample characteristics STROBE: 6: Give the eligibility criteria, and the sources and methods of selection of participants 14a: Give characteristics of study participants (e.g. demographic, clinical, social) and information on exposures and potential confounders CROSS: Describe the study population (i.e. background, location, eligibility criteria for participant inclusion, exclusion criteria).	6 14a	6a	3

STROBE: 12(b) Describe any methods used to examine subgroups and interactions CROSS: Describe the sampling techniques used (single stage vs multistage sampling, simple random sampling, stratified sampling, cluster sampling, convenience sampling). Specify the location of sample participants, whenever clustered sampling was applied	12b	6b	3
STROBE: Explain how the study size was arrived at CROSS: Provide information on sample size, along with details of sample size calculation	10	6c	3
STROBE: - CROSS: Describe how representative the sample is of the study population (or target population if possible), particularly for population-based surveys	Not included	6d	3
STROBE: - CROSS: Provide information of survey's timeframe, such as periods of recruitment, exposure and follow up days.	Not included	7b	3
STROBE: - CROSS: Provide information on the entry process to prevent multiple entries by single participant	Not included	7c	3
Study Preparation STROBE: - CROSS: Describe any preparation process before conducting the survey (e.g. Training, advertising the survey etc).	Not included	8	Not applicable
Ethical considerations STROBE: - CROSS: Provide information on ethical approval for the survey if obtained, including informed consent, institutional board review (HREC) approval, Helsinki declaration, GMP as required.	Not included	9a	4
STROBE: - CROSS: Provide information about the survey anonymity and confidentiality and describe what mechanisms were used to prevent unauthorised access	Not included	9b	4
Statistical Analysis STROBE: (a) Describe all statistical methods, including those used to control for confounding CROSS: Describe statistical methods and analytical approach. Report the statistical software that was used for data analysis.	12a	10a	4

STROBE: (b) Describe any methods used to examine subgroups and interactions CROSS: Report any modification of variables used in the analysis, along with reference (if any).	12b	10b	4
STROBE: (c) Explain how missing data were addressed CROSS: Report details about how missing items, missing data was handled. Include rate of missing items, missing data mechanism, and methods used to deal with missing data	12c	10c	3
STROBE: (c) Explain how missing data were addressed CROSS: State how non-responses were addressed	12c	10d	3
STROBE: CROSS: For longitudinal surveys, state how loss to follow up was addressed	Not applicable	10e	Not applicable
STROBE: (a) Describe all statistical methods, including those used to control for confounding CROSS: Indicate whether any methods such as weighting of items or propensity scores have been used to adjust for non-representativeness of the sample.	12a	10f	4
STROBE: (e) Describe any sensitivity analyses CROSS: Describe any sensitivity analysis conducted	12e	10g	3
<b>Results</b> STROBE: (a) Report numbers of individuals at each stage of study—e.g. numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (c) Consider use of a flow diagram CROSS: Report number of individuals at each stage of the study. Consider using a flow diagram, if possible.	13a 13c	11a	4
STROBE: (b) Give reasons for non-participation at each stage CROSS: Provide reasons for non-participation at each stage if possible	13b	11b	Not applicable
STROBE: Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection CROSS: Report response rate, present the definition of response rate or the formula used to calculate response rate.	5	11c	4
STROBE: - CROSS: Provide information to define how unique visitors are determined. Report number of unique visitors, along with	Not applicable	11d	Not applicable

relevant proportions (e.g. View proportion, participation proportion, completion proportion).			
<p><b>Descriptive Results</b></p> <p>STROBE: (a) Give characteristics of study participants (e.g. demographic, clinical, social) and information on exposures and potential confounders</p> <p>CROSS: Provide characteristics of study participants, as well as information on potential confounders and assessed outcomes</p>	14a	12	4
<p><b>Main Findings</b></p> <p>STROBE: (a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included</p> <p>CROSS: Give unadjusted estimates and, if applicable, confounder-adjusted estimates along with 95% confidence intervals and p values</p>	16a	13a	4 -raw data 8- LR
<p>STROBE: Report other analyses done—e.g. analyses of subgroups and interactions, and sensitivity analyses</p> <p>CROSS: For multi-variable analysis, provide information on the model building process, model fit statistics, and model assumptions (as appropriate).</p>	17	13b	Not applicable
<p>STROBE: (e) Describe any sensitivity analyses</p> <p>CROSS: Provide details about any sensitivity analysis performed. If there are considerable amount of missing data, report sensitivity analyses comparing the results of complete cases with that of imputed dataset (if possible)</p>	12e	13c	3
<p><b>Discussion/Limitations</b></p> <p>STROBE: Explain how the study size was arrived at Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias</p> <p>CROSS: Discuss the limitations of the study considering sources of potential biases and imprecisions, such as non-representativeness of sample, study design, important uncontrolled confounders.</p>	10 19	14	10
<p><b>Interpretations</b></p> <p>STROBE: Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence</p>	20	15	9-10

CROSS: Give a cautious overall interpretation of results, based on potential biases and imprecisions, and suggest areas for future study			
Generalisability STROBE: Discuss the generalisability (external validity) of the study results CROSS: Discuss the external validity of the results	21	16	9-10
Other sections Role of funding STROBE: Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based CROSS: State whether any funding organisation has had any roles in the survey's design, implementation, and analysis.	22	17	11
Conflict of interest STROBE: - CROSS: Declare any potential conflict of interest	Not included	18	11
Acknowledgements STROBE: - CROSS: Provide name of organisations/persons that are acknowledged along with their contributions to the research	Not included	19	11



## Appendix D – Semi-Structured Interview Guide

Interview guide

Welcome

Verbal consent if haven't received signed consent form

Questions

A few quick questions about you and your kids before talk about social media

How many children do you have?

What are their ages?

Would you say your children are generally healthy?

Are you married, partnered, single?

What is your highest level of education?

Do you live in the city, outer metropolitan area or in the country (regional or rural)?

1. Can you tell me about your process for finding health information for your child?  
(explore social media use and other forms of health information)
2. What would you say are the most valuable aspects of using social media for health information for your child from your experience?
3. What would you say are the most challenging aspects of using social media for health information for your child from your experience?
4. How do you determine who/what information to trust?
5. Do you act on information found on social media?
6. What healthcare practitioners do you usually take your children to when they are unwell? (explore why)

At conclusion

- An email will be sent when your transcript is ready if you wish to review it.
- Would you like to be included in the research dissemination plan? Would you like to be made aware of when the research is published or any media that may results from this research?

## Appendix E – Standards for Reporting Qualitative Research (SRQR)

### Standards for Reporting Qualitative Research (SRQR)\*

<http://www.equator-network.org/reporting-guidelines/srqr/>

	Page/line no(s).
<b>Title and abstract</b>	
<b>Title</b> - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Page 110
<b>Abstract</b> - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Page 110
<b>Introduction</b>	
<b>Problem formulation</b> - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Pages 111,113
<b>Purpose or research question</b> - Purpose of the study and specific objectives or questions	Page 112
<b>Methods</b>	
<b>Qualitative approach and research paradigm</b> - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	Pages 112, 115
<b>Researcher characteristics and reflexivity</b> - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	Page 115
<b>Context</b> - Setting/site and salient contextual factors; rationale**	Page 113
<b>Sampling strategy</b> - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	Page 113
<b>Ethical issues pertaining to human subjects</b> - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Page 113
<b>Data collection methods</b> - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	Page 114

<b>Data collection instruments and technologies</b> - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	<b>Page 114</b>
<b>Units of study</b> - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	<b>Page 114</b>
<b>Data processing</b> - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	<b>Page 115</b>
<b>Data analysis</b> - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	<b>Page 115</b>
<b>Techniques to enhance trustworthiness</b> - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	<b>Page 115</b>

#### Results/findings

<b>Synthesis and interpretation</b> - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	<b>Pages 116-125</b>
<b>Links to empirical data</b> - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	<b>Pages 116-125</b>

#### Discussion

<b>Integration with prior work, implications, transferability, and contribution(s) to the field</b> - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	<b>Pages 125-128</b>
<b>Limitations</b> - Trustworthiness and limitations of findings	<b>Page 128</b>

#### Other

<b>Conflicts of interest</b> - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	<b>Page 128</b>
<b>Funding</b> - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	<b>Page 128</b>

\*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**\*\*The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.**

**Reference:**

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014  
DOI: 10.1097/ACM.0000000000000388