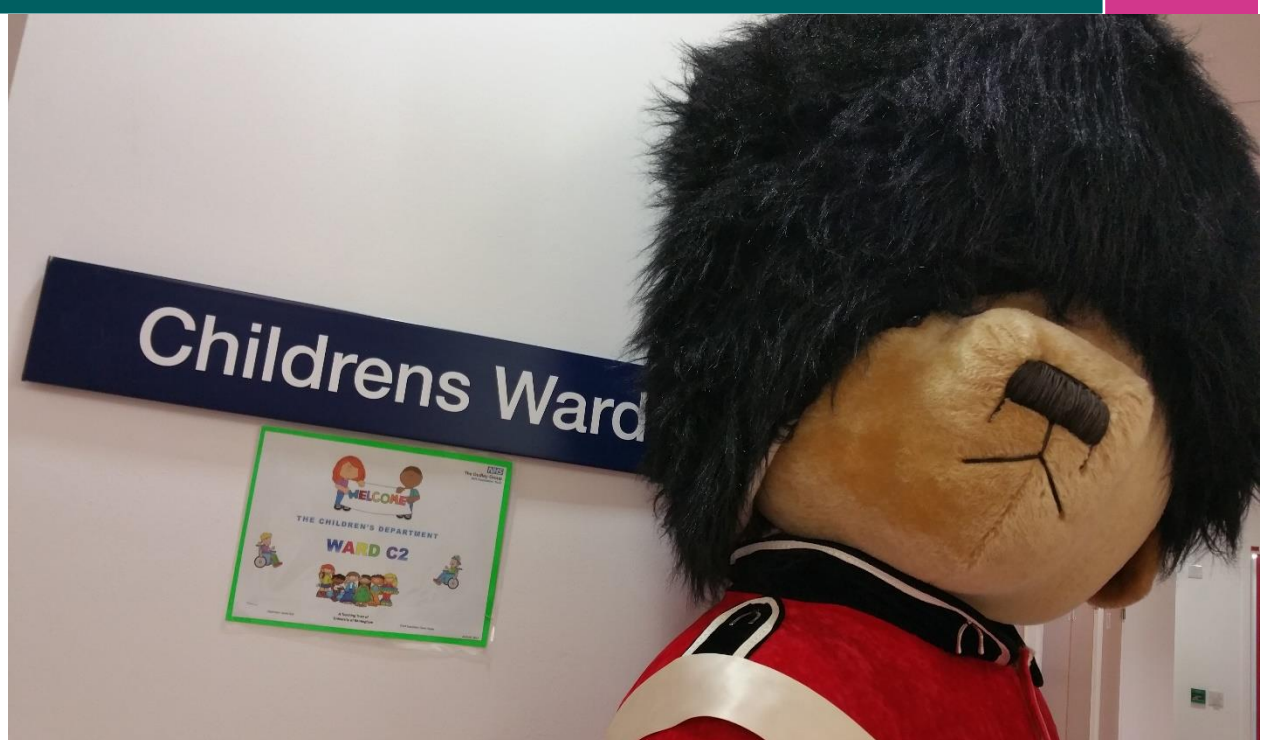


Infants and Young Children

Their healthcare journeys



A Healthwatch Dudley Report for NHS
Dudley Clinical Commissioning Group

Dr Rob Dalziel FRSA
September 2018



Response to Healthwatch

PLEASE COMPLETE AND RETURN TO HEALTHWATCH DUDLEY

	Question	Action	Responsible Person	Comments	Change state*
1	How will you target messages and information to meet the needs of: a) Mothers and female carers b) Younger parents and carers c) Parents and carers with a first child				
2	What will you do to better understand context and the ways in which: a) Parents and carers are situated in their communities b) Parents and carers live and work				
3	What will you do to improve access to general practice and: a) Better understand the needs of parents and carers b) Develop and adapt the training provided for staff c) Get practices to open for longer and at different times d) Build on the provision of services available at weekends e) Review and enhance out-of-hours services f) Reduce variability in the prioritisation of young children for appointments				
4	How will you seek to ensure: a) Parent or carer and clinician conversations avoid taking up an 'us-and-them' position b) Parents and carers are listened to c) Parents and carers questions are answered d) Unhelpful technical language is eliminated e) Inadequate explanations of what to do or what is happening are eliminated				
5	What can be done to: a) Reduce confusion around the purpose of the Russells Hall Hospital Emergency Treatment Centre and the demarcations between emergency and urgent care b) Improve the layout at the Emergency Treatment Centre to make it more welcoming c) Eliminate design features at the Emergency Treatment Centre that can restrict opportunities to get information on visitors symptoms and undertake effective triage and assessment procedures d) Improve information systems and the information made available to help visitors to the Emergency Treatment Centre using standard and innovative technological solutions e) Improve the layout and appearance of the Children's Emergency Department				
6	Healthcare pathway for infants and young children: What can be done to: a) Encourage more collaboration between different services b) Create a more joined-up approach to the provision of services c) Encourage the involvement of the public in the co-production of pathways, the design of services, and how they are delivered to meet their needs d) Eliminate unhelpful organizational and professional demarcations that are barriers to creating person-centred and seamless services				
					*Change stage: Red (outstanding), Amber (being progressed), Green (done)

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The task at hand



'We were tasked with gathering information that would help us to better understand infants and young children's healthcare journeys'.

A handwritten signature in black ink, appearing to read 'Andrea Crew'.

Andrea Crew
Chief Officer

NHS Dudley Clinical Commissioning Group asked Healthwatch Dudley if it could help with some public engagement work. The aim was to get the views of parents and carers with an infant or young child on what happens when they are unwell.

We needed to assess what sorts of healthcare help and advice parents and carers were getting. And how they might use online and telephone based services or talk with healthcare professionals face-to-face.

The aim was to gain an impression of what is good or not so good in the way that healthcare services for infants and young children are set up and function.

This report sets out what we did and our findings. In turn, it elaborates on what the implications are for healthcare services policymakers and managers. Where appropriate we highlight good practice and actions that would help to improve services.

Inquiry in brief

The NHS Dudley Clinical Commissioning Group asked Healthwatch Dudley to get parents and carers views on what they do when an infant or young child is unwell. And the healthcare journeys of those infants and young children.

Parents and carers can get access to advice and help from other family members or friends, the internet (and maybe the NHS website), the NHS 111 telephone advice line, community pharmacy, general practice, and hospital based urgent and emergency care services.



Conversations

A conversation pack was developed that Healthwatch Dudley staff and volunteers used to get parent and carer views on the healthcare journey of their infant or young child who was unwell. We were at the Russells Hall Hospital, at different times, over a period of seven days. And went into the Emergency Treatment Centre to visit the Urgent Care and Children's Emergency Department waiting areas. In addition we visited the hospital's Paediatric Assessment Unit. In total we collected 43 stories, talking to 43 mothers and 18 fathers with, on occasion, other family members also included in the conversations.

Findings

Firstly, context is important. Mothers and other female carers remain responsible for much childcare. So, targeting them for their views and improving understanding of what information and support they need to help them when a child is unwell is likely to be particularly useful. At the same time, parents and carers have family

and work commitments to contend with, that are quite different to what existed even in the quite recent past, which impact on decisions about what to do when a child is unwell.

Secondly, there is unhelpful variation in the quality of information and help available for parents and carers when an infant or young child is unwell. Importantly, parents and carers must have a high level of trust in the information and advice they get if it is to prevent them from, perhaps inappropriately, bypassing particular parts of the healthcare system.

Thirdly, there are issues to do with the types of conversation that parents and carers might have with healthcare professionals and others. They need to feel they have been listened to, their questions have been properly answered, and the advice they have received is helpful and reassuring.

Fourthly, getting help could be more straightforward. It is not always clear to parents and carers what they should do or what is happening. The distinctions and demarcations, for example, between emergency care and urgent care are not always clear or well understood. A lack of good information means parents and carers are sometimes more anxious than they need be about their child's welfare.

Fifthly, more can be done to develop a healthcare pathway, for infants and young children, which is clear and works effectively for parents and carers - delivering appropriate care and treatment, at the right time, and in the right place.

CHAPTER ONE

Background

The NHS Dudley Clinical Commissioning Group tasked Healthwatch Dudley with gathering parents and carers views, on the healthcare journeys of infants and young children when they are unwell. The intention being to improve understanding of why parents and carers decide to take different types of action and approach different healthcare services for help when a child is unwell.¹

‘Respecting the role of parents is a significant part of providing services for children and young people. It is important to ensure that the views of parents are sought and their concerns responded to’.

Core Standards, National Service Framework for Children, Young People and Maternity Services, Department for Health, 2004

Healthwatch

In 2013, Healthwatch was set up, in line with proposals outlined in the Health and Social Care Act 2012.

Healthwatch England has its own National Director and board. And there are 148 local Healthwatch

organizations forming a network that extends across England.²

Healthwatch Dudley is a champion for local people on health and social care matters. In turn, it is interested in gathering people’s stories on how they get access to health and social

¹ In this report an infant is aged 0 to 1 year and a young child is aged 1 to 4 years.

² Healthwatch England, <http://www.healthwatch.co.uk/>

care advice or services.³

Its board decides on strategy and sets priorities for action to improve understanding of how health and social care services are working (or not) in the Dudley borough.

Dudley borough

The Dudley borough is centrally located within the Black Country. It includes the three main towns Dudley, Halesowen and Stourbridge.

However, locally the borough is divided into five townships: Brierley Hill (and Kingswinford); Dudley and Netherton; Sedgley; Halesowen; and Stourbridge. The 2011 census estimated the borough population to be 312,925.

Most people (88.5%) describing themselves as White British. But other significant ethnic groups are: Pakistani, Indian, Polish, Latvian, Lithuanian, and Caribbean.

Meanwhile, the number of people aged 65 and over is higher than both regional and national averages (18.6% compared to 16.9% regionally and 16.3% nationally). And the number of

older people, as a proportion of the population is expected to continue to increase over time.⁴

People's health is mixed compared with the England average. Life expectancy in the most deprived areas of the borough is 9.5 years lower for men and 5.8 years lower for women than in the least deprived areas.⁵

NHS Dudley Clinical Commissioning Group

The NHS Dudley Clinical Commissioning Group is responsible for planning and commissioning (buying) health services for people living in the borough.

Services that it commissions include: elective hospital care; rehabilitation care; urgent and emergency care; and most community health care.

Its operational and long-term strategic plans set out how it intends to deliver and develop safe, high quality health care. It remarks that these plans have been drawn up following discussions with staff and clinicians, the public, the local

³ Healthwatch Dudley, <http://www.healthwatchdudley.co.uk>

⁴ 2011 Census Area Profile for Dudley www.dudley.gov.uk/2011census

⁵ Dudley Unitary Authority, Health Profile 2014, Public Health England: <http://www.apho.org.uk/resource/item.aspx?RID=142215>

authority, and voluntary and community sector organizations.

It has a vision for health and social care in the future that includes a

radical redesign of the local healthcare landscape and changes to the way people access healthcare services.⁶



⁶ NHS Dudley Clinical Commissioning Group, www.dudleyccg.nhs.uk/

In 1996, a paper on research with the parents of young children, and what happens when they are ill, appeared in the British Medical Journal. It describes how important it is for parents to have control and a sense of being able to deal with the effects of illness, which is impacted by their knowledge, beliefs and experiences that help to determine how they will manage a problem or situation.⁷ Meanwhile, the Department of Health, in its National Service Framework for Children, Young People and Maternity Services, published in 2004, remarks that parents and carers must *'Receive the information, services and support that will help them to care for their children and equip them with the skills they need to ensure that their children have optimum life chances and are healthy and safe'*.⁸

In 2017, a report on emergency care for children and young people, jointly produced by the Health Foundation and the Nuffield Trust, remarked that *'There are a range of complex reasons why children and young people, their families and carers may seek emergency care from a hospital ... they range from socioeconomic and demographic factors (for example, population change) to changes in policy that affect the availability and quality of services. They also include changes in people's perceptions and experience of the services'*.⁹ The Royal College of Paediatrics and Child Health, in a report produced in 2018, commented that there was a need for more integrated and joined up healthcare services for children and that progress depended on *'Collaborative commissioning ... and the ability to think beyond organisational turfs toward networked pathways of care which transcend barriers'*.¹⁰

⁷ Kai, J (1996) 'General Practice - What worries parents when their preschool children are acutely ill, and why: a qualitative study, BMJ, Vol313, 1996, https://www.jstor.org/stable/29733202?seq=1#page_scan_tab_contents

⁸ Crown Copyright 2004, Department of Health, National Service Framework for Children, Young People and Maternity Services, Core standards, <https://www.gov.uk/government/publications/national-service-framework-children-young-people-and-maternity-services>

⁹ Keeble, Eilis and Kossarova, L (2017) 'QualityWatch, Focus on: Emergency hospital care for children and young people: What has changed in the past 10 years?', The Health Foundation and Nuffield Trust, <https://www.nuffieldtrust.org.uk/research/focus-on-emergency-hospital-care-for-children-and-young-people>

¹⁰ Royal College of Paediatrics and Child Health (2018) 'Facing the Future: standards for children in emergency settings', <https://www.rcpch.ac.uk/resources/facing-future-standards-children-young-people-emergency-care-settings>

Getting access to advice and help?

Healthcare, infants and young children

There are a number of different ways that parents and carers, in the Dudley borough, can get access to advice and help when an infant or young child is unwell. They can, where it is possible and practical approach other family members or friends. In turn, they may undertake an internet search or go directly to the NHS website for information and help. Then there is the NHS 111 telephone advice line, community pharmacy, general practice and the Emergency Treatment Centre at the Russells Hall Hospital. Some parents and carers may choose or need to use healthcare services outside of the borough.

Family and friends

When an infant or young child first seems unwell a parent or carer might first approach another family member or friend for advice and help.

Grandparents are often involved in caring for infants and young children and sometimes aunts and uncles or other members of the extended family.

Alternatively, a neighbour or other friend may be the first port of call for a parent or carer seeking advice on what to do when an infant or child is unwell.

In turn, the advice and help received may be more or less useful depending on the circumstances and the nature of any symptoms or illness.

Internet search

An internet search, where a parent or carer posts a healthcare question or description of symptoms online, can mean they get quick access to a whole mass of healthcare information.

This information is provided by various more or less well known and reliable organizations and experts or other individuals including parents and carers themselves.

NHS website

There are more than 48 million visits per month to the NHS website (formerly known as the NHS Choices website). It aims to help people have more control of their health and wellbeing.

Parents and carers can access it to get access to relevant and reliable information on the health and wellbeing of infants and children.

They can use its A to Z guide to get advice on conditions and treatments or what to do when an infant or young child is unwell.

Parents and carers can find services in their area (pharmacy, dentist, general practice, accident and emergency department or other urgent care service). And it is possible to book appointments on line.

The site also provides comparative data about healthcare providers, to help people make informed choices about healthcare.¹¹

NHS 111 telephone service

If someone is worried about an urgent medical concern they can call the NHS 111 telephone advice line.

Its trained staff can be contacted 24 hours a day, 7 days a week. They will ask questions to assess symptoms and can advise on self-care, pass a caller to a nurse, dentist or doctor or

¹¹ NHS website:
<https://www.nhs.uk/about-us/about-the-nhs-website/>

arrange for a face-to-face meeting with a healthcare professional.

Alternatively, a staff member might provide information on a local service that can help with a healthcare concern. However, if it is decided an ambulance is needed they can send one immediately.¹²

Community pharmacy

There are 67 community pharmacies in the Dudley borough where parents and carers can get advice and help when an infant or young child is unwell.

Each day around 1.6 million people visit a community pharmacy on the high street, at a supermarket or in a shopping mall. A number are open for extended hours.

In recent years the role of the pharmacy has been changing to focus more on preventing illness, health checks, and taking pressure off general practice.

They are able to help the public with assessing conditions and making decisions about what care

or medicines they need. At the same time, pharmacists have been developing clinical services, such as, the management and monitoring of long term conditions including asthma, diabetes and high blood pressure.¹³

General practice

In the Dudley borough there are 64 general practice premises.

General practice is designed to provide high quality care and undertakes 90 per cent of contacts with people accessing health services to get help and advice on their health and wellbeing.

The practice provides comprehensive and person-centred health care to people in their communities, keeping detailed records of individuals' medical histories.

And GPs and practice teams provide vital services for people through every stage of their life.¹⁴

¹² NHS 111: <https://www.nhs.uk/using-the-nhs/nhs-services/urgent-and-emergency-care/nhs-111/>

¹³ Pharmaceutical Services Negotiating Committee: <https://psnc.org.uk/psncs-work/about->

[community-pharmacy/](https://www.rcgp.org.uk/training-exams/discover-general-practice.aspx)

¹⁴ Royal College of General Practitioners: <http://www.rcgp.org.uk/training-exams/discover-general-practice.aspx>

Emergency Treatment Centre

At the Russells Hall Hospital a new Emergency Treatment Centre was opened in April 2018.

It includes GP-led urgent care services and is adjacent to existing adults and children's emergency departments - to create a single point of access for people to urgent and emergency treatment.

People who walk in through the Emergency Treatment Centre front entrance approach the nurse streaming desk and are directed to either the Urgent Care or Emergency Department waiting areas, depending on their clinical need.¹⁵

Urgent care

Urgent care is non-emergency help for people who have minor illnesses and injuries that need prompt attention. The urgent care facility is open 24 hours a day, seven days a week.

It is staffed by GPs and nurse practitioners. Some of the conditions treated here are: minor burns and bites; fever and raised temperatures;

sickness and vomiting; irritation and rashes; mild breathing difficulties; and cuts and scrapes.¹⁶

Children's Emergency Department

The Children's Emergency Department waiting area is a short walk from the Emergency Treatment Centre. It has books and toys and is open 24 hours a day.

Paediatric Assessment Unit

There is a Paediatric Assessment Unit at the Russells Hall Hospital, which is a component of urgent and emergency care for children.

For an acutely unwell infant or young child it is a dedicated facility providing assessment, observation and treatment, without the need for inpatient admission.

Different triage and diagnostic tools are used to help to determine a child's illness and understand its nature and severity.

Inclusion and exclusion criteria are applied to ensure that only those with illnesses that can be suitably managed by the resources available (including

¹⁵ The Dudley Group NHS Foundation Trust: Emergency Treatment Centre: <http://dudleygroup.nhs.uk/work-starts-emergency-treatment-centre/>

¹⁶ Dudley Group NHS Foundation Trust: Urgent Care Centre: <http://dudleygroup.nhs.uk/services-and-wards/urgent-care-centre/>

staff and equipment) are seen at the unit.

These can include: asthma; respiratory tract infections; gastroenteritis; poor fluid intake; fever; rash; minor head injuries or trauma; abdominal pain; seizures; accidental poisoning; intoxication;

self-harm and injury; and post procedure sedation.¹⁷

In addition to the services described parents and carers may approach other healthcare professionals for help including a midwife, district nurse or health visitor.



¹⁷ Royal College of Paediatrics and Child Health: Standards for Short-Stay Paediatric Assessment Units:

<https://www.rcpch.ac.uk/search?keywords=paediatric+assessment+unit>

CHAPTER TWO

What we did

We needed to get parent and carer stories on what happens when an infant or young child seems unwell. The aim was to find out more about the healthcare journey: the decisions made on where to go to get help and advice; information on the quality and usefulness of that help and advice; and how it shapes the next steps in the healthcare journey.



Conversation pack

A conversation pack was developed to help interviewers to gather information when they had conversations with parents and carers on the healthcare journeys of infants and young children (see Appendix, on page 46).

The pack included details of the project and its purpose to be read out to the parent or carer and a section to be completed to show that they had understood what had been said and consented (or not) to continue. The next sections were designed to record information about the interview and its location, the parent

or carer, and the infant or young child. Then there was space to record the details of the story. The final section was a record of the number of interactions with different healthcare services.

Briefing volunteers

We held a briefing session for volunteers who had indicated they were keen to help. It covered the purpose of the project, details about how it was intended to capture information on conversations, and plans for working at the Russells Hall Hospital. Volunteers were also provided with advice and notes on how to conduct conversations:

listening, avoiding leading questions and judgemental responses, and the use of prompts to confirm or clarify what had been said. Finally, they were advised of arrangements for meeting transport and subsistence costs.

At the hospital

Healthwatch staff and volunteers were at the Russells Hall Hospital for a week from Monday 9 July to Sunday 15 July, 2018. We were there at different times of the day and night. We spent time in the Emergency Treatment Centre (in the Urgent Care and Children's Emergency Department

waiting areas) and the Paediatric Assessment Unit.

In each of the areas of the hospital we spoke with parents and carers and made notes on the environment and what was happening round about. At the same time, it was possible to have conversations with some hospital staff in between talking to parents and carers.

Who we talked to

In total we gathered 43 stories, talking to 41 mothers and 18 fathers with, on occasion, other family members included in conversations as well.

Number of Conversations = 43	
Mother	41
Father	18

We gathered 12 stories in the Urgent Care waiting area, 21 stories in the Children's Emergency Department waiting area, and 10 stories at the Paediatric Assessment Unit.

Location	
Russells Hall Hospital Emergency Treatment Centre: Urgent Care	12
Russells Hall Hospital Emergency Treatment Centre: Children's Emergency Department	21
Russells Hall Hospital: Paediatric Assessment Unit	10

The ages of the 59 people, who indicated they were the mother or father of an infant or young child, that we had conversations with varied. However, 36 were aged 30 or under and of these 20 were aged 20 or under.

Age	Mother	Father
16-20	1	0
21-25	14	5
26-30	11	5
31-35	9	4
36-40	5	3
41-45	1	1
Total	41	18

Regarding postcode area there were parents and carers from across the Dudley borough area and a few from outside of the area. The small numbers of mean it is not possible to be confident about there being any significant patterns in where parents and carers were resident.

Postcode area			
DY1	4	B62	2
DY2	7	B63	1
DY3	6	B64	2
DY5	4	B65	2
DY6	1	B69	2
DY8	9	WV5	1
DY9	1	Total	43

Of the 43 infants or young children, whose healthcare journeys were discussed in conversations with their parents or carers, 23 were female and 20 were male.

Infant/Young Child: Gender		
Female	Male	Total
23	20	43

We collected information on the healthcare stories 43 infants and young children. Of these 26 were aged 13 months or younger, with 14 aged 6 months or younger. In 16 instances they were a first child. ¹⁸

Infant/Young Child: Age (months)			
0-6	14	28-34	3
7-13	12	35-41	2
14-20	2	42-48	1
21-27	8	60	1
Total			43

¹⁸ Much of the literature on infants and young children defines an infant as 0 to approximately 1 year old, and a young child as being aged between 1 and 4 years.

In total, there were 30 White British infants and young children. And 11 infants and young children from other ethnic backgrounds.¹⁹

Infant/Young Child: Ethnicity			
White British	30	Other Mixed Background	1
Indian	1	White and Black Caribbean	2
Other White Background	2	Other Asian Background	1
White and Asian	1	Pakistani	3
Total			41



¹⁹ Not all parents and carers answered the question on ethnicity

Infants and young children were registered at various general practices in the Dudley borough. A few were registered at general practices outside of the Dudley borough area.²⁰

Infant/Young Child: General Practice			
Three Villages Medical Practice	3	Links Medical Practice	1
Thorns Road Surgery	2	Wordsley Green Doctors Surgery	2
New Street Surgery (West Bromwich)	1	Central Clinic	2
Cross Street Health Centre	1	Keelinge House Surgery	2
Stourside Medical Practice	1	Wychbury Medical Practice	2
Lion Health	1	Rangeways Road Surgery	1
A W Surgeries	1	Eve Hill Medical Practice	1
Clement Road Medical Centre	1	Bath Street Medical Centre	2
Regis Medical Centre	4	Gravel Hill Surgery (Wombourne)	1
Meadowbrook Road Surgery	1	Portway Family Practice (Oldbury)	1
Waterfront Surgery	1	Greens Health Centre	1
Churchview Surgery	2	Summerhill Surgery	1
Ridgeway Surgery	3	Chapel Street Medical Centre	1
Stepping Stones Medical Practice	1	Total	41

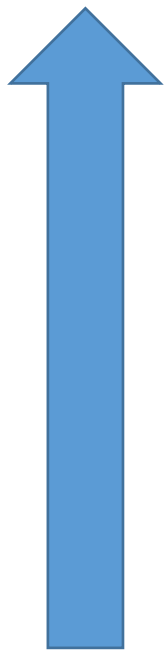
²⁰ Not all of the parents and carers answered the question on what general practice their infant or young child was registered at.

CHAPTER THREE

What we found

In this section we elaborate on the stories collected around the healthcare journeys of infants and young children when they are unwell. We start with the parents and carers and their initial decisions on what to do to get help and advice. And track their progress through a system with different opportunities to interact with online, telephone, pharmacy, general practice and hospital based services.

Higher levels of abstraction - the interpretation of meaning



Lower levels of abstraction - close to text

Overarching theme

Healthcare journey of an infant or young child: parent or carer view

Theme

Just another cog in a system

Theme

Staff actions and non-actions

Theme

Feeling alone

Categories & Coded units

Confused about what will happen next

Text

'We were not told how long we would wait or how we would get the help we wanted'

A diagrammatic representation of the process of content analysis: analysing text to identify coded segments of conversation or text, which can be grouped into categories (containing similar or connected items of information). Then themes can be identified that emerge from the categories or relations between categories.

We used a combination of discourse and content analysis to make sense of the detail in the stories that were collected. It facilitated the careful labelling of portions of text and words or phrases. Then the identification of categories comprised of assorted but related material and families (groups of categories) that help to explain people's behaviour and decision-making (see diagram on page 23).

At the same time, regard was given to the context in which parents and carers find themselves when they are trying to get help for an infant or child who is unwell.

The start of a journey

Parents and carers are likely to be quite anxious and worried when an infant or young child is unwell: *'It's worrying when they are very young and can't tell you how they are feeling or what is wrong'*; *'Our six-month old baby ... [was] coughing and wheezing so we [were] worried'*; *'[We were] worried because she had mottling on her arms and feet and her lips were blue'*.

Meanwhile, our conversations with parents and carers show it was mainly mothers and female carers who bear a significant amount of responsibility for childcare - and seeking help and advice when an infant or young child is unwell. And a high proportion of parents and carers (36 out of 59) were aged under 30. Out of a total of 43 infants and young children 26 were aged 13 months or less.

Going straight to hospital

Parents or carers will sometimes be so concerned about the wellbeing of an infant or young child that they decide straightway to go to hospital: *'I had just noticed the spots were worse ... so came straight here to the Urgent Care Centre'*; *'Because [my] son's temperature was so high [I] took him straight to hospital rather than go to the GP'*; *'[I] drove to hospital ... [I] wanted [my] daughter to be seen to be on the safe side as [I] was aware of the signs of sepsis ... [she] was lethargic and not her usual self'*.

They may also end up at hospital if they feel it is going to be difficult to get access to a GP or an appointment at the general practice.

'I knew that I probably would not get an appointment with my GP ... so I thought I might as well bring [my son] here [to the hospital] ... but obviously I would prefer to see my GP'.

Parent/carer of a boy aged 1

It can be problematic getting access to a GP, despite there being examples of good practice, and general practitioners doing much to try to ensure infants and young children get prompt and effective care and treatment when they are unwell.

General practice

Some parents and carers gave examples of good experiences when they need to contact their general practice: *'When we ring the GP they have emergency slots for under-fives which is good'; 'Because she is under five years of age the GP [will see] her on the same day that we telephone for an appointment'.*

But, other parents and carers told us about the difficulties they experience trying to get access to their general practice and help for their unwell infant or young child: *'On Friday I rang the GP and was told the surgery was busy and there were no appointments. I waited until Saturday then decided to come to the Urgent Care Centre'.*

'She has been complaining of stomach ache. We have been self-medicating. We rang the GP ... There were no appointments available for two weeks. We were told to leave things for two or three days and it was probably an infection and would clear up on its own'.

Parent/carer of a child aged 2

'We went to the doctor's surgery and they could see the baby being sick. But they would not give us an appointment, saying they were fully booked but they had our details. So go home and we will phone or text'.

Parent/carer of a girl aged 2 weeks

'I phoned my GP [in the] morning but I could not get an appointment for my baby. It is really hard to get appointments at my surgery and Monday's are particularly bad'.

GP referrals to hospital

In some instances a member of the general practice team advises a parent or carer to take an infant or young child that is unwell to hospital.

'She had been unwell for a couple of days with a high temperature and rash. I telephoned the GP ... They said they had no appointments available ... The doctors' surgery told us to go to the Urgent Care Centre'.

Parent/carer of a child aged 7 months

'[I] called the GP but was told there were no appointments that day until six in the evening ... [and told] to contact the hospital'.

Parent/carer of a boy aged 5



At other times, a parent or carer has contacted the general practice and either straightaway or later decides to go to hospital, rather than trying to contact the general practice again.

'[I] phoned the GP surgery. They said a GP would call back. But [I] thought it would be best to go to accident and emergency instead of waiting'.

Parent/carers

'[My] son has been crying out the last couple of nights. He has had ear infections on and off since last November. [We] went to see the GP who checked his ears and they were okay. But [later we] realized his temperature was high and he was holding his privates so [we] brought him to the hospital'.

Parent/carers

NHS 111 and ambulance service

Some parents and carers, visiting hospital, have first contacted the NHS 111 telephone advice line for help and been advised to go to hospital or an ambulance had been called on their behalf. In a few instances they had made a direct call to the ambulance service.

'At about three thirty in the morning [I] phoned [NHS] 111 as [my daughter had been] crying in the night ... and did not want a bottle and just wanted a cuddle. She had a high temperature, was burning up. [NHS] 111 advised to get [her] checked out at the Urgent Treatment Centre'.

Parent/carer

'[At] about six thirty in the evening [I] called [NHS] 111 as her breathing had changed. They listened to her over the phone and then called an ambulance, which came within fifteen minutes. The paramedics checked her over and were not sure so they brought us up to the Children's Emergency Department'.

Parent/carer

At the same time, there were parents and carers who remarked that they felt they had not had a uniformly good experience when they contacted the NHS 111 service: *'They asked a whole lot of questions on how she was ... did they need to ask all of the questions ... in the end they said go to accident and emergency ... the conversation overall took eleven minutes'.*

'At about three in the morning he was really bad. [I] rang [NHS] 111. They said a doctor would ring back within thirty minutes. But they didn't phone for about two hours and the phone only rang twice. [We] were trying to sort out [our] son so did not get to the phone in time to answer it. It was a withheld number so [we] couldn't ring back. So had to ring [NHS] 111 again and [we were] told that the case had been closed as we hadn't answered the phone. So [we] had to go through all the details again'.

Parent/carer

At the Emergency Treatment Centre

For the different reasons, already outlined, parents and carers can end up at the hospital Emergency Treatment Centre. Then they are directed to either the Urgent Care or Children's Emergency Department waiting areas.

Urgent Care Centre

It can be relatively straightforward procedure at the Emergency Treatment Centre and urgent care reception, with only a short time to wait before an infant or young child is seen by a clinician: *'We arrived at three in the afternoon and came through the Emergency Treatment Centre ... [at urgent care] a doctor looked at him straightaway and sent us into the Children's Emergency Department...'* However, at busy times it can be a long wait and there is only sparse information available on waiting times and what a parent or carer can expect to happen next.

'Came [to Urgent Care Centre] just after eleven in the evening registered and waiting for about thirty minutes so far. Not told how long [to wait] but there is a hand written sign on the Urgent Care Centre desk stating waiting time is two to two and a half hours even though there is not many people in here'.

Parent/carer

Some parents and carers go to the Emergency Treatment Centre with an unwell infant or young child who is seen by a clinician at the Urgent Care Centre. They then return home but quite quickly return to the Emergency Treatment Centre.

'[I] came with her to the hospital yesterday and was sent home. But came back today as her temperature was high'.

Parent/carer of a young girl

'A week has gone by and there is still inflammation and soreness. So I have come back to the Urgent Care Centre today'.

Parent/carer of a young girl

Children's Emergency Department

Parents and carers can be directed from the Emergency Treatment Centre to the Children's Emergency Department. Alternatively, they can come to the department using an emergency ambulance. Again a visit to the department can be relatively straightforward for parents and carers.

'It's been okay since we got here [the Children's Emergency Department]'.

Parent/carer of a young girl

'[We] were took into a cubicle quite quickly, and seen by a nurse and a doctor straightaway. [They] did the observations and we were told that they did not need to take any more blood tests. They are waiting for urine sample, which will then be tested'.

Parent/carer of a young girl

However, a parent or carers experience visiting the department may not, in the end always be so straightforward or good.

'At the Children's Emergency Department [we] sat in a cubicle for about thirty to forty minutes, as there were no spare seats in the waiting area. We were then told [it] might be better [for us] to be seen in the Urgent Treatment Centre. We were there for about two hours and forty minutes and [our daughter] was seen by a doctor who then rang the Paediatric Assessment Unit who said to come up for [her] breathing to be monitored'.

Parent / carer



PAU

The Paediatric Assessment Unit

It is possible for a general practitioner to directly refer an infant or young child into the hospital's Paediatric Assessment Unit. Alternatively, they can be sent there from the Children's Emergency Department.

'[We are] satisfied the procedure to get [our] daughter to hospital was quick, due to the GP contacting the hospital and referring us to them'.

Parent/carer of a young girl

'[Our] daughter has been unwell for a few days, she had a fit last night ... [We] went to the GP ... who then rang the hospital and booked us into the Paediatric Assessment Unit'.

Parent/carer of a girl aged 6 months

Once at the Paediatric Assessment Unit parents and carers tended to remark that overall their experience of getting help for their unwell infant or young child was good.

'When I came upstairs I was only in the Paediatric Assessment Unit for a few minutes before someone saw me. They took swabs and I think they might do more tests. So I'm back in the waiting area to see a doctor'.

Parent/carer of a boy aged 1

'It's been good on the Paediatric Assessment Unit so far, just waiting for observations. They are monitoring her temperature and heart rate ... If all okay [we] can go home. But [we] have been told we have forty-eight hours when we can get access to the ward, ring or come in to ask for advice, which is reassuring'.

Parent/carer of a young girl

Getting information and finding your way

One recurring message from parents and carers emphasises there are aspects of the healthcare system that are overly complicated and difficult to understand. They can have a good experience when they visit the hospital and the Emergency Treatment Centre.

'I like the Urgent Care Centre, it is fantastic and supportive with the information they provide. It is a twenty-four hour service and they have helped me and my children'.

Parent/carer of a girl aged 2

But, getting access to information and support is not always easy to do in circumstances where a parent or carer is anxious and worried about the wellbeing of an infant or young child.

'[I] had to repeat the same story over and over again to different staff as my daughter was moved around the hospital'.

Parent/carer of a young girl

'It's bad that when you get to the ... desk in the Urgent Care Centre [that] you have to fill in a form, rather than talk to someone and they write [things down] ... [I] told them why [I] was there and they asked [me] to pick up my daughter to show them. Then they gave [me] a form to fill in. But this could be precious minutes that are wasted ... there was no triage ...'.

Parent/carer of a young girl

In turn, there are parents and carers who remark that they are not kept well enough informed about what was happening when they take an unwell infant or young child to hospital: *'It did not seem clear why or how some children go to the Urgent Care Centre and some go to the Children's Emergency Department'; '[I] challenged the doctor and said my son had been crying all day ... [I] asked that he be taken to an assessment unit and checked properly'.*

'[I] lost patience with the hospital staff because of having to wait so long ... [I] constantly had to keep asking what was happening'.

Parent/carer of a boy aged 8 months

Hospital environment and care

The new Emergency Treatment Centre at the hospital opened in February 2018.

'It's better than the old Urgent Care Centre. It's got a front door, looks cleaner, and it is not far to walk'.

Parent/carer of a boy aged 1

However, when we visited the hospital, during a warm week in July, parents and carers were commenting on and complaining about the heat in the Urgent Care and Children's Emergency Department waiting areas. In particular, the Children's Emergency Department is a small space with no windows that can get very busy.

'The [Children's Emergency Department] waiting area could be nicer ... It would be a good idea to have a quiet room and cots so little ones can have a nap whilst waiting'.

Parent/carer of a boy aged 2

Meanwhile, parents and carers often told us about their good experiences of getting help for an unwell infant or young child when they got to see a clinician at the hospital: *'We are happy with the service...'*, *'They [hospital staff] were very good with my son'*, *'We have been very happy with our experience so far'*, *'Staff were very helpful ... [we] felt things had been efficiently dealt with'*.

'Very happy with the experience. The doctor saw us and gave his opinion ... then got a second opinion, just to make sure, which was reassuring'.

Parent/carer of a young boy

Some parents and carers, though, did not, in their view, have such good experiences of getting help for their unwell infant or young child. *'[I was] frustrated at [my child] not being referred anywhere for further investigation'*, *'I feel aggravated at having to wait so long to be seen. Then when you are seen it is only for a few minutes and you are rushed on'*.

Children's ED



'[I] think [my daughter] should have been diagnosed quicker as [there have been] lots of visits to the GP'.

Parent/carer of a young girl

Other parents and carers commented: *'There is not enough staff and they are always rushing about', 'We are not happy ... other people went into the [Children's] Emergency Department whilst [we] were sitting in the Urgent Care Centre', '[I] would never come back to Russells Hall Hospital ... [I] would take my children to Birmingham ... even though it would take longer to get there'.*

What it all means

Parents and carers tend, not unexpectedly, to be quite anxious and worried, when an infant or young child is unwell. Babies and younger children cannot describe symptoms or say anything about how unwell they feel. It can be very difficult for a parent or carer to know how unwell they really are.

The importance of context

Mothers and other female carers remain responsible for much childcare. So, targeting them for their views and improving understanding of what information and support they need to help them when a child is unwell is likely to be particularly useful. Especially if it can raise awareness of the help that is available and when and how to get access to it.

At the same time, fathers and male carers must be kept informed and able to get access to help for an unwell child when they need it.

The knowledge and experience that parents and carers have of childcare will impact on what they decide to do when an infant or young child is unwell. It seems there is a tendency

for younger parents and carers to get overly anxious and go straight to the hospital.

A focus on understanding what information and help younger parents and carers need, will help to ensure they are able to make well informed choices about what to do next, when an infant or young child is unwell.

Meanwhile, parents and carers have family and work commitments to contend with, that are quite different to what existed even in the quite recent past. They can make quite a difference to how easy or not it is for them to get access to information and help when an infant or young child is unwell.

In many instances, there are also fewer opportunities for parents and

carers to ask other family members for help when a child is unwell, since they do not live close by. And they may not know their neighbours well.

It may be the case that it is a single parent or lone carer who is looking after an infant or young child. In turn, they are more likely, than in the past, if they are working, to be on shifts or variable hours' contracts, for all parents and carers it can be difficult to get time off work to take a child to an appointment at the general practice.

Where two parents or carers are looking after a child they may be working shifts or variable hours which, again, makes it difficult for them to get to an appointment at the general practice when it is open.

In many instances parents and carers need to get the siblings of an unwell child to and from nursery or school in addition to trying to get an appointment at the general practice. An increasing number of parents and carers are also helping to care for older parents or other family members, which can further complicate matters.

It is likely the targeting of healthcare messages and support, to help parents

and carers in these different situations, will help them to navigate the healthcare system more effectively. However, this action alone is not sufficient to deal with unhelpful barriers in that system.

Unhelpful variation in the quality of information and help

There are particular issues to do with infants and young children up to about the age of one. And even more so where it is a first child.

Again it is about how easy (or not) it is to get access to helpful information on healthcare options and advice on what to do when a child is unwell. Crucially, parents and carers must have a high level of trust in the information and advice if it is to prevent them from bypassing particular parts of the healthcare system.

Information and support for parents and carers, on what to do when a child is unwell, should be made available during pregnancy and, perhaps, even before. And it should be possible to adapt and change it according to home circumstances and the subsequent development of the new born child.

Parents and carers who are sometimes confused and made more worried by the technical language and medical explanations that healthcare services staff use. They can be left feeling not listened to and there is an increased possibility that they will be making unnecessary visits to the general practice or the hospital.

Meanwhile, many parents and carers find it so difficult to get access to help at the general practice that they do not try to contact it in the first instance, when an infant or young child is unwell. Instead, they decide to go straight to hospital.

There is work being done to review general practice and look at opening times and how appointment systems work. Nevertheless, parents and carers can still experience difficulties getting the help they need when a child is unwell. Indeed, some are advised to go to the hospital because there are no appointments available for them.

Not enough empowerment

Then there are issues to do with the types of conversation that some parents and carers have with healthcare staff. Where they do not work well there is a risk parents and

carers end up in inappropriate parts of the healthcare system.

Once again, parents and carers need to feel they have been listened to, been given trustworthy advice, and that their child's welfare has been paramount in any discussions that have taken place. At the same time, any messages on healthcare must be articulated in an empathetic and understandable way.

When parents and carers feel they have not been listened to and their views have been ignored or not properly considered, their questions have not been answered, or they cannot understand what is happening with their child's healthcare they are likely to be left feeling anxious, confused and angry.

Parents and carers can quickly lose trust in particular aspects of the healthcare system, which they will try to bypass in the future. Once trust is lost it can be very difficult to win back.

The risk is that some parents and carers may simply default to using parts of the healthcare system when an infant or young child is unwell, whether it is right for them or not.

Getting help could be more straightforward

When parents and carers contact the NHS 111 telephone helpline they can be very satisfied with the help they receive. Where an infant or young child is involved it can include a referral to the Emergency Treatment Centre or an ambulance being called to take them to hospital.

More research is needed to establish the appropriateness or not of NHS 111 referrals of infants and young children to hospital. What is apparent is the circumstances can be difficult when parents or carers are anxious, a very young child is unwell, and it is uncertain what might be wrong with them.

There are parents and carers who do not have a good experience when they call the NHS 111 helpline. They wonder, for example, why some questions are asked or feel it takes too long to complete the call and decide on what to do next. There is a tension between the need to gather sufficient detail on symptoms and keeping parents and carers engaged and satisfied with the progress that is being made.

It is not always clear to parents and

carers what is going to happen next. And delays in getting back to them with promised follow-up calls can be particularly upsetting.

In such circumstances parents and carers can quickly lose confidence in the service and decide not to use it in future.

At the Russells Hall Hospital there is some confusion caused amongst healthcare professionals and parents and carers over the purpose of the new Emergency Treatment Centre.

The distinctions and demarcations between emergency care and urgent care are not always clear or well understood. This situation is not helped by the fact that everyone turning up on foot at the hospital must go through the Emergency Treatment Centre entrance.

Some visitors to the centre will be expecting prompt help for what they believe to be a healthcare emergency (in line with what the hospital signage is telling them) and be concerned when they are directed to the Urgent Care Centre area to wait to be seen by a clinician.

At the Emergency Treatment Centre getting help for a child can be quite

straightforward and parents or carers are satisfied with what happens regarding the child that they have brought into the hospital that is unwell.

At busy times, the situation can be quite different in the Emergency Treatment Centre. The waiting areas get full with visitors in the Urgent Care Centre overflowing into the Adult Emergency Department waiting area. At the same time, it can be difficult for someone with a pushchair or anyone in a wheelchair to easily get access to the reception and waiting areas.

It is, to some extent, unclear as to why the centre is set out in the way that it is. There are two separate desk areas with high counters and protective glass separating staff from visitors. The layout risks creating avoidable confusion for visitors and an 'us and them' situation that can cause increased visitor frustration and even anger that could be prevented through the design of a more friendly and welcoming hospital environment.

The way that the reception area is set out can mean that at busy times when staff are under pressure there is an increased likelihood that the scope of any initial questions put to visitors or

the triage of symptoms (including those of infants and young children) is reduced.

Again, there is an issue with information, which could be much improved at the Emergency Treatment Centre, for parents and carers and other visitors.

A lack of information means parents and carers will be more anxious than need be the case. And concerned about what is going to happen next with the care or treatment of their infant or young child.

It is possible to use different modern communications technologies in innovative ways to keep parents and carers (and others) well informed about matters such as waiting times, staff on duty, and relevant healthcare advice and updates.

Names could be shown on monitor screens with details on where to go and the clinician you will be seeing. This would be particularly helpful in busy and noisy waiting areas. Some of the technology could be interactive to allow parents and carers to search out material that is helpful for them.

Parents and carers are not always provided with the information and

reassurance on their child's healthcare that will prevent them from quickly returning to the centre for more advice and help.

Meanwhile, the Children's Emergency Department it is a small, windowless, and cramped space. At times parents and carers with their infants and young children spill out into adjacent cubicle and treatment areas.

Building a better pathway

More must be done to develop a healthcare pathway, for infants and young children that are unwell, which is clear for parents and carers. And is effective in delivering appropriate care and treatment, at the right time, and in the right place.

For the pathway to work well there must be an increased provision of high quality, targeted, information for parents and carers. It must be easily accessible and in formats that are convenient to use and easily understandable to the layperson.

The pathway must clearly set out and describe what parents and carers can expect from different healthcare services. And precisely how their child will be helped.

There is scope for different healthcare services to be more collaborative and joined-up than they currently are. The aim should be to eliminate unhelpful organizational and professional demarcations that raise barriers to creating the healthcare pathway and prevent the further development of the person-centred approach to providing healthcare services.

Future discussions on children's health and getting access to help when they are unwell must include much more co-productive activity. The intention being to get parents and carers fully and effectively involved in the design of services that will meet their needs and thinking about how they should be delivered.

CHAPTER FIVE

What's next?

In this final section of the report recommendations for action are set out. They are derived from the analysis of information obtained from conversations with parents and carers and emerging themes.

Recommendations

- 1 How will you target messages and information on what to do when an infant or young child is unwell to meet the needs of:
 - a) Mothers and female carers
 - b) Younger parents and carers
 - c) Parents and carers with a first child
- 2 What will you do to better understand context and the ways in which:
 - a) Parents and carers are situated in their communities
 - b) Parents and carers live and work
- 3 What will you do to improve access to general practice and:
 - a) Better understand the needs of parents and carers
 - b) Develop and adapt the training provided for staff
 - c) Get practices to open for longer and at different times
 - d) Build on the provision of services available at weekends
 - e) Review and enhance out-of-hours services
 - f) Reduce variability in the prioritisation of young children for appointments
- 4 How will you seek to ensure:
 - a) Parent or carer and clinician conversations avoid taking up an 'us-and-them' position
 - b) Parents and carers are listened to
 - c) Parents and carers questions are answered
 - d) Unhelpful technical language is eliminated
 - e) Inadequate explanations of what to do or what is happening are eliminated
- 5 What can be done to:
 - a) Reduce confusion around the purpose of the Russells Hall Hospital Emergency Treatment Centre and the demarcations between emergency and urgent care.
 - b) Improve the layout at the Emergency Treatment Centre to make it more welcoming

- c) Eliminate design features at the Emergency Treatment Centre that can restrict opportunities to get information on visitors symptoms and undertake effective triage and assessment procedures
- d) Improve information systems and the information made available to help visitors to the Emergency Treatment Centre using standard and innovative technological solutions
- e) Improve the layout and appearance of the Children's Emergency Department

6 Healthcare pathway for infants and young children

What can be done to:

- a) Encourage more collaboration between different services
- b) Create a more joined-up approach to the provision of services
- c) Encourage the involvement of the public in the co-production of pathways, the design of services, and how they are delivered to meet their needs
- d) Eliminate unhelpful organizational and professional demarcations that are barriers to creating person-centred and seamless services

Recommended future research

It might be useful, at some point in the future, to consider undertaking;

- Further research, over a longer period of time.
- To obtain a more in-depth, longitudinal, perspective on what parents and carers are saying happens when an infant or young child is unwell.
- Such research would enable a greater number of people to be involved in conversations, perhaps at different times of the year, to reflect any seasonal changes in the way that services are delivered.

In turn:

- Dedicated research work could be undertaken in the primary care setting.
- To improve understanding of what happens, in the sector (and especially general practice), when an infant or young child is unwell.
- The intention would be to have conversations with parents and carers, clinicians and other staff (though it is likely to be necessary to also have further conversations with other providers of healthcare advice and help including NHS 111 and hospital based staff to get their views on collaboration, healthcare pathways, and making services more joined-up).

Finally:

- Research could be undertaken that is specifically focused on healthcare pathway development.
- Involving collaboration between the public, healthcare professionals and relevant others and the co-production and co-design of healthcare pathways and healthcare services for infants and young children.
- Where changes are made to the way services are set up and delivered then it would be useful to undertake follow-up research, to get parents and carers views on whether the advice and help that they get, when a child is unwell, has improved or not.

Appendix

Infants and Young Children's Healthcare Journeys

INTERVIEWER TO READ TO PARENT/CARER:

Hello my name is I work/volunteer with Healthwatch Dudley.

We would be very grateful if you could share with us your views on getting access to medical advice or help for a child when they seem to be unwell. This should take between 5 to 10 minutes to do.

Dudley Clinical Commissioning Group, which plans for how local health services will be provided, has asked Healthwatch Dudley, the health and social care champion for people using such services, to gather parents and carers views.

You can choose whether you want to take part and you have the right to withdraw at any time. If you have a question or are uncertain about anything we will do our best to help or take time to explain.

What you tell us will remain confidential unless information is disclosed that indicates someone is at risk of harming themselves or others. Such information may be passed on to some other relevant organization for them to deal with.

Parents, carers and young children will not be identifiable in any report that is produced.

TO BE READ BY PARENT/CARER:

Consent

I have been given the information above and understand what will happen as part of the discussion about Infants & Young Children's Healthcare Journeys.

I confirm I have been given an opportunity to ask questions about the project and am satisfied with the answers provided. I confirm I have not been coerced into giving consent, and it has been given freely and voluntarily.

Interviewer

Name

	Reference	
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Interview location

GP surgery	UCC	A&E/ED	PAU

UCC: Urgent Care Centre, A&E/ED: Accident & Emergency/Emergency Department, PAU: Paediatric Assessment Unit

Other (specify)

--

Date

Day	Month	Year

Time

Hrs	Mins	AM/PM

Interviewee (parent or carer)

All questions are optional

First person

Relationship to child

--

Gender

Female	Male

Other (specify)

--

Age

--

Home address
postcode (first part)

--

Second person

Relationship to child

Gender

Female	Male
<input type="text"/>	<input type="text"/>

Other (specify)

Age

Home address
postcode (first part)

Infant or young child

All questions are optional

Gender

Female	Male
<input type="text"/>	<input type="text"/>

Other (specify)

Age

Between 0 and 4 years
<input type="text"/>

Ethnicity

White British	<input type="text"/>
White Irish	<input type="text"/>
Gypsy/Traveller	<input type="text"/>
Any other White background	<input type="text"/>
White and Black Caribbean	<input type="text"/>
White and Black African	<input type="text"/>

White and Asian	<input type="text"/>
Any other mixed background	<input type="text"/>
Indian	<input type="text"/>
Pakistani	<input type="text"/>
Bangladeshi	<input type="text"/>
Any other Asian background	<input type="text"/>

Caribbean	<input type="text"/>
African	<input type="text"/>
Any other Black background	<input type="text"/>
Chinese	<input type="text"/>
Arab	<input type="text"/>
Prefer not to say	<input type="text"/>

Other ethnic group (specify)

Home address: postcode (first part)

Doctors' surgery

Is this a first child?

Yes	<input type="text"/>	No	<input type="text"/>
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Interviewee (parent or carer): contact with services

To be completed by Healthwatch Dudley staff after the interview has ended

Service	Number of contacts (tick a box for each time there was a contact with a service)						Total
NHS Choices							
NHS 111 telephone advice line							
Pharmacist							
General Practitioner							
Health Visitor							
Urgent Care Centre							
Emergency Department							
Paediatric Assessment Unit							
Emergency Ambulance							

Other (specify)

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Other (specify)

--	--	--	--	--	--	--

--	--	--	--	--	--	--

Other (specify)

--	--	--	--	--	--	--

--	--	--	--	--	--	--

Other (specify)

--	--	--	--	--	--	--

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Grand Total	
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If a parent or carer would like to talk more with Healthwatch Dudley:

Contact details:

Name:

Tel:

Address:

.....

Healthwatch Dudley would like to especially thank all of the parents and carers with experience of and views on the healthcare journeys of infants and young children who took part in conversations at the Russells Hall Hospital. And the Healthwatch Dudley volunteers who helped to make the project a success.

Also, Caroline Brunt, Chief Nurse, NHS Dudley Clinical Commissioning Group; Simon Bousfield, Nursing Lead, Children's Ward, Dudley Group NHS Foundation Trust; Ahjali Dave, Directorate Manager, Women and Children, Dudley Group NHS Foundation Trust; Ned Hobbs, Director of Operations, Surgery, Women and Children, Dudley Group NHS Foundation Trust; and Julie Pain, Head of Nursing, Dudley Group NHS Foundation Trust for their cooperation and help.

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