

Interview descriptors

Table 1: Where interviews were undertaken

	Parents	Young adults	Deprived
Home	13	6	12
University	3	9	3
Phone interview	0	1	0
Carer's workplace	0	0	1

Table 2: Interview participants' socio-demographic details

	Parents	Young adults	Deprived	Total
Gender				
Male	2	5	8	15
Female	14	11	8	33
Age				
18-20	0	2	0	2
21-30	4	14	0	18
31-40	10	0	5	15
41-50	2	0	0	2
51-60	0	0	2	2
>60	0	0	9	9
Length of residence in city				
<1 year	0	1	0	1
1-5 years	5	4	1	10
>5 years	11	11	15	37
Ethnicity				
White - British	9	14	10	33
White - European	1	0	1	2
White – Latin	1	0	0	1
Asian/Asian British – Pakistani	1	1	1	3
Asian/Asian British – Chinese	0	1	1	2
Asian/Asian British – Afghan	0	0	1	1
Asian/Asian British – Indian British	0	0	1	1
Black African/Caribbean/Black British - African	3	0	1	4
Black African/Caribbean/Black British – Caribbean	1	0	0	1
Marital status				
Married/living as married	12	3	9	24
Separated/divorced	0	0	3	3
Single/not married	4	13	3	20
Widowed	0	0	1	1
Children?				
Yes	16	4	12	32
No	0	12	4	16

Employment status				
Working full time	2	5*	3	10
Working part time	8	4**	2 [§]	14
Student (full time)	0	6**	2	8
Homemaker (full time)	3	0	0	3
Retired	0	0	9 [§]	9
Temporarily unemployed, seeking work	2	2 ⁺	0	4
Permanently unemployed (illness/independent means)	0	1	1	2
Other – unemployed/unemployed due to bad health	1	1 ⁺	0	2
Other – self-employed and part-time study	0	1*	0	1

* One young adult working full time and Other – self-employed and part time study

** Two young adults working part time and full time students

⁺ One young adult temporarily unemployed and Other – unemployed due to bad health

[§] One deprived person retired and working part time

Table 3: Interviewee HLQ mean scores and ranges for each subgroup

Setting	Parents (n=16)	Young adults (n=15)	Deprived (n=15)
Ability to actively engage with healthcare providers	4.24 (3.4 – 5)	3.93 (3 – 4.6)	3.92 (2.8 – 5)
Understand health information well enough to know what to do	4.31 (3.6 – 5)	4.29 (3.6 – 5)	3.99 (2.2 – 5)

Interview participant consent form



The
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Sheffield S1 4DA

Participant Interview Consent Form

**Drivers of Demand for Emergency and Urgent care services (The *DEUCE* study):
understanding patients' perspectives of seeking help for healthcare**

Please
initial
box

1. I confirm that I have read and understand the information sheet dated 17/07/17, Version 2 for the above project. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that I am consenting to participation in an interview.
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical or legal rights being affected.
4. I understand that should I withdraw from the study any data already collected will be used unless I say otherwise
5. I give permission to be audio recorded for the purpose of this research
6. I understand that all information is confidential, except if I disclose that my or somebody else's health is at serious risk. In this instance the researcher will discuss the situation with a health specialist and inform the appropriate services.
7. I understand that all identifying information will be removed from my responses, making them anonymous before analysis. I give permission for researchers to have access to my anonymised responses in this or other ethically approved studies.
8. I understand that quotations of what I say may be used in the research report or other publications, after they have been anonymised.
9. I agree to take part in the above research project.

Name of Participant

Date

Signature

Name of person taking consent

Date

Signature

Interview participant information sheet



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30 Regent Street

Drivers of Demand for Emergency and Urgent care services (The DEUCE study): understanding patients' perspectives of seeking help for healthcare

Participant Information Sheet (Interview)

Before you decide whether to take part in this study, it is important for you to understand why it is being done and what it would involve for you. Please take time to read the following information and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the research?

The purpose of this research is to find out how people make decisions about using emergency and urgent healthcare. For example, ambulance services, an A&E department, or a GP.

Why have you been chosen?

You have been chosen because you recently attended or used an emergency or urgent care service.

Do you have to take part?

It is up to you to decide. The information provided here will help you to make that decision. We will also discuss this information with you again and ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This will not affect any future care you may receive.

What will happen if I take part?

You will be invited to attend one interview with a researcher who will ask about your experiences of using the service which you recently attended and how and why you made the decision to use that service. We'd like the interview to take place within one week of your healthcare episode as this may help you to remember what was happening at the time of the health problem. The interview will be about an hour long and will take place at a time and place that is convenient for you. For example, the researcher could undertake the interview in your own home or we could arrange to pay your travel expenses if the interview took place away from your home (for example, at a local community or University building).

The interviews will be audio-recorded with your permission. You can ask for the audio recorder to be turned off during the interview if you no longer want the information you are giving to be recorded. Audio recordings will be listened to and transcribed before being destroyed.

What are the possible benefits and risks of taking part?

While there are no immediate benefits in taking part, it is hoped that valuable information will be gained about how the public make decisions about the services they use so that health services are better able to understand the needs of patients.

Is the research confidential?

Personal information will be only be known by a few members of the research team. Any personal or identifying information such as names will be removed as the interviews are transcribed. Some of the information from the interviews may be quoted but all quotes will be anonymised so that they are not identifiable to you.

The only exception to this will be if you tell the interviewer information that indicates that your or somebody else's health is at serious risk, or in the unlikely case that any form of malpractice by staff is revealed. In this situation, the researcher will discuss this with other research team members and, if necessary, with a NHS staff member to make a decision as to whether any further action needs to be taken. If this is required, action is likely to be taken immediately, but you would be informed.

What will happen if I don't want to carry on with the study?

If you decide that you do not want to continue, you can withdraw at any time. Unless you tell us otherwise, we will keep and use any information you have given us up to that point.

Who will have access to the data and where will it be held?

All the data will be held in confidence by the research team at the University of Sheffield. If you decide to take part in an interview your name and any personal details provided by yourself, for example telephone number or email address, will be stored at the University to allow us to contact you to arrange an interview appointment, and to share our findings with you at the end of the study if you wish. Following this, your personal details will be destroyed. If you decide not to take part in an interview, we will destroy your personal details as soon as you indicate that you do not wish to take part.

Personal details recorded on paper, including your signed consent form, will be kept in a locked filing cabinet, in a lockable office. Personal details recorded electronically will be stored on a password protected computer, held in a lockable office. All data will be stored at the University of Sheffield.

What will happen to the results of this research?

The results will be presented to government organisations, health service providers, user-led organisations, and published in research journals. None of these publications will enable a reader to identify study participants.

What if something goes wrong?

If by participating in this research you have any questions, please contact the Project Manager Emma Knowles (details given at the end). This type of research is not considered to be harmful. In the unlikely event that you feel you have been harmed by taking part in this research, there are no special compensation arrangements. If you do wish to complain or have any concerns about how you have been approached or treated in the course of this study you can contact (Professor John Brazier, Dean of ScHARR)

Expenses and payments

We appreciate the time you have spent helping us with our study. As a small 'thank you' for taking part in this study we will provide you with a £20 shopping gift voucher on completion of the interview. This can be spent in a variety of local shops. We will also reimburse any reasonable travel expenses, if the interview takes place in a non residential setting (ie at University premises).

Who is funding the research?

This research is funded by the National Institute of Health Research (NIHR - www.nihr.ac.uk). The work is being undertaken at the University of Sheffield in the School of Health and Related Research.

Has the research been approved by an ethics committee?

The study has been approved by London Brent Research Ethics Committee. The reference number for the study is: 17/LO/1228.

Who should I contact for further information?

Emma Knowles, DEUCE Project Manager, School of Health and Related Research, University of Sheffield, Tel: 01142220781; E-mail: e.l.knowles@sheffield.ac.uk

Study webpage: <https://www.sheffield.ac.uk/scharr/sections/hsr/mcru/deuce>

Letter to potential interview participants

Date

Dear

Thank you very much for your interest in our research study about how people make decisions about using emergency services.

I have enclosed a copy of the study information sheet which provides more details about what the study will involve for you. I have also enclosed a consent form for you to have a look at, which we would ask you to complete at the interview if you decide to take part. Please feel free to talk about the study with friends or relatives, and if you have any questions please contact me (details below).

I will call you again in a few days to see whether you would like to take part in the research and, if so, to arrange an interview. Your treatment will not be affected in any way by your decision.

Yours sincerely,

Researcher on the DEUCE study

Direct telephone: 0114 222

email:

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Topic guide for interviews

Thanks for taking part. Should take less than an hour, will be recorded.

We are trying to understand more about how people make decisions when they are seeking care from an urgent or emergency health service. The main focus of the interview today will be to think about what led you to contact x service for the recent issue you had.

Some of these things will seem really obvious to you, but everyone is different and I don't know anything about you, so bear with me!! Any questions before we begin?

1. Thinking about your recent episode [at service]. Can you say a little about what happened?

Probe:

- What was the health problem?
- How long had you experienced symptoms?
- Had you tried any self-care?
- Was it a problem experienced before?
- Was there anything that particularly worried you about the situation?

2. You made contact with [X service] on [day of week]. Was there a reason why you made contact on that particular day/time? (ie rather than on another day that week/another time that day)

Probe:

- Urgency of health problem
- Work commitments, childcare
- Transport [if appropriate]
- Why at that particular time of day? Had something changed?

3. Prior to contacting the service, had you sought help from anywhere else?

Probe:

- Any other services you tried to access by phone or in person? Where and when?
- What was the outcome? Has that happened before when you've tried to get help from this service?

4. Were there any other health services which you *think could have* helped with your problem?

Probe:

- Did you think about other options? Suggest options if they don't mention (list other options depending on problem, service contacted and location e.g. NHS 111, walk-in centre, minor injuries unit, out of hours GP etc)
- Were you aware of these, why did you choose not to make contact?
- What did you think would have been different if you had contacted them?
- Have you tried contacting this service in the past? Did this affect your decision?
- Did you look online for information/advice? If so, did this affect your decision about what to do?

5. Did anyone else help you decide what to do?

Probe:

- Who did you talk to about what was happening? Family, friends...
- Did they have the same view of your problem (same, more/less serious etc?)
- Did anyone else have any different suggestions about what you did?
- If you disagreed with them, how did you decide what to do?

6. So, we've been exploring this particular incident in detail. Thinking more generally, I'd like to ask you a bit more about how you use healthcare services. Generally when you are ill, what is your usual source of healthcare?

Probe:

- What are the reasons why this is your usual source? Convenience, confidence
- How do you decide where you go to get help?
- What other services have you used?

7. What did you think would be best about x service for you on this occasion compared to other options/ services?

Probe:

- Anything particular they could offer or anything that the others don't offer?
- Have you ever used this service before? Did this make a difference to your decision?

8. We've been talking today about emergency and urgent care services, and we're interested in finding out what people think these words mean.

Probe:

- What do you think is the difference between emergency and urgent care?
- What things about your situation made you decide it was urgent/an emergency?

9. Final question for this part - are there any changes that could be made to the current health system to make it easier for you to access health care?

Probe: availability of services and information.

10. Do questions from the validated Health Literacy Questionnaire (HLQ) – give to the person to fill in if they are happy, or ask the questions with the response sheet. Leave anything blank if not happy to answer.

11. Demographic questions – give to person to fill in, or ask questions if they prefer. Again, leave anything blank if not happy to answer.

Focus group consent form



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Focus Group Participant Consent Form

Drivers of Demand for Emergency and Urgent Care services (DEUCE): understanding patients' and public perspectives

Please
initial
box

1. I confirm that I have read and understand the information sheet dated (31/05/18), Version 2.0 for the above project. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that I am consenting to participation in a focus group.
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical or legal rights being affected.
4. I understand that should I withdraw from the study any data already collected will be used unless I say otherwise.
5. I give permission to be audio recorded for the purpose of this research
6. I understand that all information is confidential, except if I disclose that my or somebody else's health is at serious risk. In this instance the researcher will discuss the situation with a health specialist and inform the appropriate services.
7. I understand the importance regarding the confidentiality of other participant's discussions in the focus group. I agree to keep the discussion confidential, and not share any aspect of the discussion with anyone outside of this group.
8. I understand that all identifying information will be removed from my responses, making them anonymous before analysis. I give permission for researchers to have access to my anonymised responses in this or other ethically approved studies.
9. I understand that quotations of what I say may be used in the research report or other publications, after they have been anonymised.
10. I agree to take part in the above research project.

Name of Participant

Date

Signature

Name of person taking consent

Date

Signature

Focus group participant information sheet



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Drivers of Demand for Emergency and Urgent care services (The *DEUCE* study): understanding patients' perspectives of seeking help for healthcare

Participant Information Sheet

Before you decide whether to take part in this study, it is important for you to understand why it is being done and what it would involve for you. Please take time to read the following information and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the research?

The purpose of this research is to find out how people make decisions about using emergency and urgent healthcare. For example, ambulance services, an Emergency Department, or a GP.

Why have you been chosen?

You have been chosen because you recently attended an Emergency Department or contacted a general practice, or have taken part in an earlier phase of the study.

Do you have to take part?

It is up to you to decide. The information provided here will help you to make that decision. We will also discuss this information with you again and ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This will not affect any future care you may receive.

What will happen if I take part?

You will be invited to attend one focus group with approximately seven other participants. A researcher will lead a discussion about how the general public make decisions about using healthcare, and explore factors that may impact on how you make decisions. The focus group will last around 2 hours and will take place at the University of Sheffield.

The focus group will be audio-recorded with your permission. You can ask for the audio recorder to be turned off during the discussion if you no longer want the information you are giving to be recorded. Audio recordings will be listened to and transcribed before being destroyed.

What are the possible benefits and risks of taking part?

While there are no immediate benefits in taking part, it is hoped that valuable information will be gained about how the public make decisions about the services they use so that health services are better able to understand the needs of patients.

Is the research confidential?

We will ask the other participants of the focus group to keep the discussion confidential.

Personal information will only be known by selected members of the research team. Any personal or identifying information such as names will be removed as the focus group is transcribed. Some of the information from the focus group may be quoted but all quotes will be anonymised so that they are not identifiable to you.

What will happen if I don't want to carry on with the study?

If you decide that you do not want to continue, you can withdraw at any time. Unless you tell us otherwise, we will keep and use any information you have given us up to that point.

Who will have access to the data and where will it be held?

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Expenses and payments

We appreciate the time you have spent helping us with our study. As a small 'thank you' for taking part in this study we will provide you with a £30 shopping gift voucher on completion of the focus group. This can be spent in a variety of local shops. We will also provide refreshments during the focus group.

Who is funding the research?

This research is funded by the National Institute of Health Research. The work is being undertaken at the University of Sheffield in the School of Health and Related Research.

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Project webpage: <https://www.sheffield.ac.uk/scharr/sections/hsr/mcru/deuce>

Topic guide for focus groups: parents' version

Total time: (2hrs to 2hrs 30 mins) [Questions slightly adapted for each focus group]

Introductions and plan for the focus group (10 minutes)

On arrival

Tea/Coffee

Name badge/consent forms

Vouchers issued at end of discussion/toilets/fire exits/discuss until around 11.30 –lunch – further short discussion.

- Introduce myself
- [Lindsey] is here with me today and she may take some notes – this will help when we come to analyse the results.
- Thank you for joining us today. We are researchers at the University of Sheffield, and are trying to understand how people make decisions when using emergency and urgent health care. Today we'd like to talk about things which may improve access to health services, or things which might help people to provide self-care rather than contacting a service when faced with an urgent health problem.

We've invited you here today because we want to understand this from the perspective of parents with young children. So, as you respond to questions today try to answer them from the perspective of a parent (rather than an adult seeking care for themselves).

- My role today – ask questions and listen to what you have to say. I'll ask a question and I'd like you to discuss your opinions amongst yourselves – almost like I'm not here. We've got a lot to get through today so there may be points where I come in to move us along to the next question.
- May have differing experiences and it's important that everyone gets a chance to talk. We're using a tape recorder today to make sure we don't miss anything you say.
- Try to speak as clearly as possible, and for the benefit of the tape recorder it would be helpful if one person speaks at a time.
- Obviously non verbal responses will not be picked up by the tape recorder so try not to shake/nod your head instead of saying yes/no.
- No right or wrong answers. You may have differing views. That's fine.
- Lastly, what is said here today should remain confidential. I'll use your first name during the discussion if that's ok but you won't be identified in any reports that we write, and we ask that you don't share what others have said today, outside of the group. Whatever you say in this discussion will not affect any care that you have in the future.

1. (15 minutes) We've recruited you following an attendance at the A&E department (or your general practice).

First of all, it would be useful to hear your views of A&E/general practice. When seeking care for your child what do you like about A&E/general practice?

<i>Prompts</i>	<i>Convenience</i>	opening hours, location, access (ie no appointment necessary)
	<i>Satisfaction with care provided</i>	based on own experience/family & friends, availability of services provided (i.e. x-ray), perceived expertise of doctors

2. a. (60 minutes) We hear in the news about health services being under pressure - lots of patients attending and staff struggling to keep up with the demand. Thinking how to reduce the number of people **calling the 999 ambulance service**, what suggestions would you have to reduce demand for **emergency ambulances**? [Thinking particularly about parents of young children, like yourselves] Are there alternatives to calling 999 that parents could use, or are there possible alternatives that could make easier for parents with young children to use?

[Focus group facilitator to list potential interventions on a flip chart/screen]

<i>Prompts</i>	<i>Pharmacy</i>	knowledge about which medications can be bought without prescription, is pharmacist a usual source of health advice?
	<i>NHS 111</i>	awareness of what NHS111 can provide, confidence in advice
	<i>General practice</i>	changes to the appointment system, extended opening hours, ability to see a GP of your choice, video appointments, being able to speak to a GP rather than a receptionist.
	<i>Walk in centre</i>	knowledge about opening hours and the services provided (ie x-ray)
	<i>Non service level factors</i>	support from family?
	<i>Self-care</i>	on reflection, could anything enable parents to try and care for the problem at home without accessing a health service? Increasing health/medication knowledge – understanding symptoms/dosage limits? First aid course?

- b. Replace 'Ambulance service' with '**General Practice**' alternatives that could reduce demand for general practice
- c. Replace 'Ambulance service' with '**A&E**' alternatives which could reduce demand for A&E

10 minute break with refreshments.

3. (30 minutes) Looking at the potential interventions listed, if you were allowed to change just one thing that would make accessing care easier for you (as a parent of a young child), which would it be and why?