

Parent/Carer Interview Guide

Research study: Parents' perceptions of Antibiotic USE and antibiotic resistance (PAUSE)

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Ethics reference:

Topics to be explored: Below is a list of questions to be discussed in this study. The work will remain flexible with respect to participants' agendas but we will cover the topics. It is common in semi-structured work to develop topics and questions as new ideas emerge from early data collection. Therefore, we may add new topics as the interviews progress and data collection continues. However, the key topic of parents' and carers' views and understanding about the role of antibiotics and the significance of antibiotic resistance when their young child has a respiratory tract infection, will remain the same.

Briefing:

- 1) Thank participant for agreeing to take part.
- 2) Introduce self.
- 3) This interview is for the PAUSE study. The aims were described in the participant information sheet. People differ in their understanding about the role of antibiotics when they or their family are unwell. There is actually very little information available about how parents consider the benefits and harms of antibiotics, specifically about the risk of antibiotic resistance. It's these differences that we'd like to hear about and we would value your unique perspective.
- 4) If at any time during the interview you do not wish to answer a question that's okay.
- 5) I would like to digitally record our conversation. The recording will be typed out, but everything you say will be anonymous. Your name and any names you mention, and any places you mention will be taken out, so that if someone read your interview they would not know who you are or where you work.

- 6) Your interview will remain confidential, unless (as discussed and outlined in the consent form) it is possible that you or someone else is at risk, but this will be discussed with you first.
- 7) If, at any stage, you wish to stop the audio recorder, please let me know.
- 8) Do you have any questions?

Note: Name of child will be used where indicated by [child].

SECTION A

- 1. Tell me about the last time [child] was unwell (poorly) with a respiratory tract infection (e.g. chest, ear or throat infection) and what you did to help him/her get better.**
- 2. Can you tell me about how [child] had been feeling and the symptoms that he/she had?**

Prompts: How long had he/she had symptoms for? Why do you think they got ill? What did you think caused the illness? What were you most worried about?

- 3. What did you (or anyone else do) initially to try to help [child] get better?**

Prompts: What did you do at home to help [child]? What medicines did [child] take? Who gave you advice about how to look after [child]?

- 4. What (other) sources of advice did you use to help you take care of [child]?**

Prompts: Who did you speak to about how to care for your child? What information did you look up and where did you find this?

- 5. Did you visit a healthcare provider to get advice about [child's] infection?**

If **YES**, why did you decide to visit the GP/OOH service/other? What were you most concerned about? [then go to 7]

If **NO**, why did you decide not to visit the GP or other health care service? [then go to 6]

6. Can you tell me about any other time you have been to see a doctor or nurse about a similar illness for your child? [then go to section B]

Prompts: What advice did they give you? What did you think of the advice that you got?

7. What happened when you took [child] to see the doctor or nurse?

Prompts: How did you expect the doctor (or nurse) to help [child]? How did you feel about the advice they gave you? What did you think about the treatment they recommended?

8. Was [child] prescribed antibiotics by any healthcare professional during their visit?

Prompts: Did you expect an antibiotic to be prescribed by the doctor or nurse? Did you think [child] needed an antibiotic?

If prescribed an antibiotic, how did you feel about [child] being prescribed an antibiotic?

If not prescribed an antibiotic, how did you feel about [child] not being prescribed an antibiotic?

SECTION B

I'd now like to ask you a few questions about antibiotics.

9. Can you tell me a little bit of what you know about antibiotics in general?

Prompts: What have you heard about antibiotics?

What illnesses do you think they can help treat? How do you think antibiotics work?

10. What sort of symptoms do you think need an antibiotic when you are unwell?

Prompts: Why did you think those symptoms need an antibiotic?

11. What sort of symptoms do you think need an antibiotic when [child] is unwell?

Prompts: Why did you think those symptoms need an antibiotic?

12. How do you feel about [child] taking antibiotics?

Prompts: What benefits do you think there are to taking antibiotics? What concerns do you have about [child] taking antibiotics?

13. Can you tell me about possible harms or side effects that people can experience if they take antibiotics?

Prompts: What risks do you think there are when taking antibiotics?

14. Tell me a little about what you know about “antibiotic resistance”.

Prompts: Where did you hear about it? Where would you get information about antibiotic resistance?

15. Tell me what you understand about the risk of antibiotic resistance for human beings.

Prompts: How do you think antibiotic resistance comes about? In what way do you think antibiotic resistance is harmful?

16. If we focus on you for a moment, how do you think antibiotic resistance is likely to affect your personal health?

Prompts: Do you think that antibiotic resistance is likely to affect you?

17. Now, let’s focus on your family and [child]. How do you think antibiotic resistance is likely to affect [child’s] health?

Prompts: Do you think there is any difference between how antibiotic resistance is likely to affect your family compared to other parents?

Section C

Now I'd like to show you a few examples about making people more aware about antibiotic resistance in the UK.

At this point participants will be shown two examples (paper and web-based) of antibiotic public campaigns in order to facilitate discussion and elicit participants' views about antibiotic resistance (see Appendix): E-bug, Antibiotic Guardian or video clip from Dr Sally Davies <https://www.gov.uk/government/news/countrys-most-recognisable-doctors-explain-antibiotic-resistance>.

18. How do these materials make you feel?

Prompts: What do you think about these leaflets or message? Is there anything new here, or that you haven't heard before? What surprises you about this information?

19. How would you change these materials to make them better?

Prompts: What would you want these materials to say? What would make you take notice of them?

20. Is there anything you personally can do to reduce antibiotic resistance?

Prompts: Do you think there is any connection between resistant bugs and the antibiotics [child] swallows? How do you think the antibiotic medicine you take relates to antibiotic resistance?

21. What have you heard about resistant bugs or infections?

Prompts: Have you had any personal experience of the effects of having a "resistant bug"? What have you heard about "superbugs" or MRSA for example?

22. We know that antibiotic resistance is harmful because too many antibiotics are used when they probably should not have been. But using fewer antibiotics might also mean that our body needs to fight off simple infections on its own. What do you think?

Prompts: What sort of symptoms would you be happy putting up with if it would minimise the chances of antibiotic resistance? What about coughing for longer? What about earache? What sort of (RTI) symptoms would you be happy [child] having if it would minimise the chances of them developing antibiotic resistance?

23. What would you as a parent/carer like to hear on how to minimise/reduce antibiotic resistance?

Prompts: How do you think we could improve messages about the risks and benefits of using antibiotics?

Closing question

Is there anything else that I haven't asked but that you would like to tell me? Thank you for taking the time today to help our research.

Additional Information

Participant (mother/father or carer):

Age of parent:

Age of child:

Number of children in the family:

Ethnicity:

Appendix

Examples of public antibiotic awareness campaigns or messages

1. e-Bug <http://www.e-bug.eu/>
2. Antibiotic Guardian leaflet and/or 2 minute Dr Chris van Tulleken video clip on <http://antibioticguardian.com/> website which is freely available and developed by Public Health England
3. Four minute video clip of Chief Medical Officer, Dr Sally Davies <https://www.gov.uk/government/news/countrys-most-recognisable-doctors-explain-antibiotic-resistance>



e-Bug

Operated by
Public Health England



www.e-bug.eu



Key Stage 2 / Science
Years 5 & 6

Antibiotic resistance in numbers

25k The number of people who die each year across Europe from infections resistant to antibiotics

A recent study showed that the likelihood of GPs prescribing antibiotics for coughs & colds increased by 40% between 1999-2011

40%

Research has shown that only 10% of sore throats and 20% of acute sinusitis benefit from antibiotic treatment but the prescription rates are much higher than this

10%

€1.5 billion Annual EU wide cost of healthcare expenses and lost productivity due to antibiotic resistant bacteria

30 years The period of time since a new class of antibiotics was last introduced despite the fact that growing numbers of infections are resistant to antibiotics

Public Health England

European Antibiotic Awareness Day (EAAD) is a Europe-wide initiative that takes place annually on 18 November.

Public Health England (PHE) is leading the co-ordination of EAAD activities in England in collaboration with Department for Environment, Food and Rural Affairs (DEFRA), the Department of Health, devolved administrations including Public Health Wales, and other professional organisations.

PHE have established the Antibiotic Guardian campaign to help protect antibiotics and improve knowledge about antibiotic resistance.

You are invited to become an Antibiotic Guardian

As an Antibiotic Guardian, encourage others to join you in protecting antibiotics against the growing threat of antibiotic resistance at www.publichealthwales.org/antibiotic-guardian

lechyd Cyhoeddus Cymru
Public Health Wales

Protect yourself, your family and friends against the spread of antibiotic resistance.

Become an

ANTIBIOTIC GUARDIAN

www.publichealthwales.org/antibiotic-guardian

What is antibiotic resistance?

THE PROBLEM

Antibiotics treat infections by killing bacteria, but now the bacteria are fighting back. Our medicines are becoming less effective which means more deaths and more complications for people receiving treatment in hospital. We have to tackle the problem before it gets worse.

HOW THIS HAPPENED

There are many reasons why antibiotics lose their effectiveness, but here are two key ones:

Firstly, we take medicines that we don't need. Antibiotics don't help most colds or coughs get better but we still request antibiotics for them.

Secondly, we make things worse when we don't take antibiotics exactly as prescribed for instance, missing doses. Never save antibiotics for future use or give them to someone else.

WHAT CAN WE DO?

Antibiotic resistance is one of the biggest threats facing us today but you can help. Please visit www.antibioticguardian.com and find out about simple steps you can take to save our antibiotics.

A world without antibiotics

PRE-ANTIBIOTIC AGE

In a world before antibiotics, as recently as the 1930s, people often died from infections like pneumonia or meningitis. Simple medical procedures/operations were risky due to the chance of infection. Antibiotics changed that.

ANTIBIOTIC AGE

Since the 1940s our antibiotics have allowed us to fight infections and save millions of lives. But they are becoming ineffective against many infections because we aren't using them properly.

POST-ANTIBIOTIC AGE

If bacteria become 'resistant' to our antibiotics many routine treatments will again become increasingly dangerous. Setting broken bones, basic operations, even chemotherapy all rely on access to antibiotics that work. Antibiotic resistance is one of the biggest threats facing us today but we have a chance to fight back. Find out how at www.antibioticguardian.com

Antibiotic resistance - What can I do?

BE AN ANTIBIOTIC GUARDIAN

Antibiotics are some of our most precious medicines, used to treat both humans and animals. The Antibiotic Guardian campaign was launched to kick-start collective action from both healthcare professionals and members of the public to work together to slow the spread of antibiotic resistance. By pledging to become an Antibiotic Guardian you choose to perform a simple action which protects antibiotics against the threat of antibiotic resistance.

TAKE THESE SIMPLE ACTIONS

- Don't ask for antibiotics, treat your cold and flu symptoms with pharmacist advice and over the counter medicines.
- Take antibiotic exactly as prescribed, never save them for later, never share them with others.
- Spread the word, tell your friends and family about antibiotic resistance.

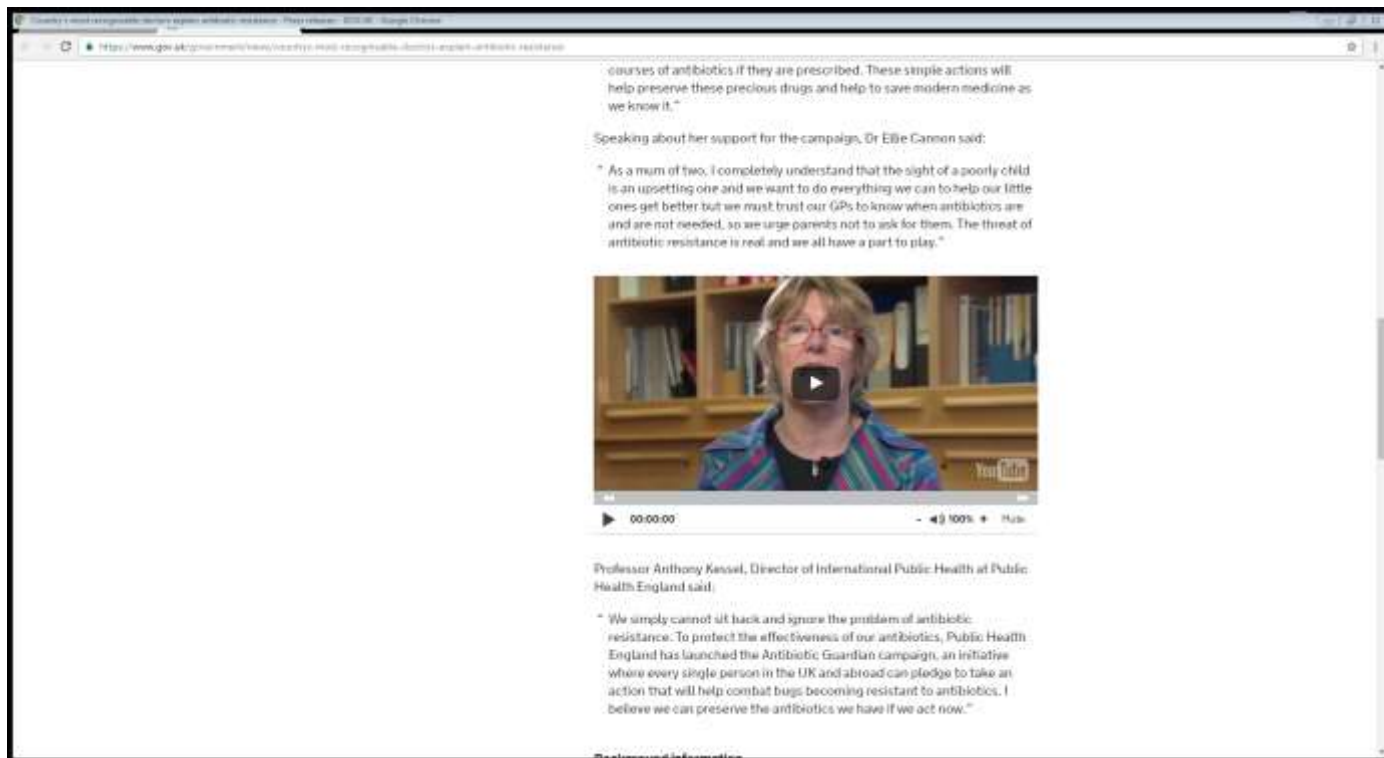
SIGN UP AND LEARN MORE

Join together at www.antibioticguardian.com and choose a pledge that feels right for you. Remember that your actions protect antibiotics.

Video screenshot of Chief Medical Officer, Dr Sally Davies

<https://www.gov.uk/government/news/countrys-most-recognisable-doctors-explain-antibiotic-resistance>

[Accessed 1 October 2016]



GP Interview Schedule

E-mail before interview

You see Lily who is 2 ½ years old as an urgent extra at the end of a Friday evening surgery. You haven't met the family before but a brief flick of the notes show that Lily was born prematurely at 32 weeks and spent a week in the special care baby unit for intravenous antibiotics. She was diagnosed with an atrial septal defect which has been asymptomatic but she continues to be seen periodically at the hospital for serial echos for this. She also has a hemiplegia under follow up with community paediatrics. Despite this she's been generally well and she isn't a frequent attender at the surgery.

Introduction

Thank for agreeing to take part.

Confirm that they know it's being recorded.

Answer any questions.

Check they've read the information about Lily.

Background information

If applicable, expand on anything in reply form which needs further information e.g. if nurses see patients with flu-like illness, how does this work (would at-risk children be put into these clinics, would they be referred on to a GP and how does this work?)

Clinical scenario

Introduce clinical scenario and reiterate that this isn't a test, no right or wrong answers, and I'm interested in finding out about what actually happens in practice and it would help me if you could be as open as possible about what happens and how you make your decisions.

Read out case:

Mum has brought her in urgently because she's concerned about Lily. She wouldn't normally bother the doctor but this "seems to be more than just a cold". She's had a runny nose, temperature and cough for the last 2 days but just this afternoon she's seemed more unwell. She can't keep her temperature down with Calpol and she's become concerned that she seems to be struggling more with her breathing, and has vomited once. She's keen to have her checked out and to see if she needs antibiotics.

So I do have some more information about Lily, but first of all I'd like know what your thoughts are, and what would or would not make you prescribe antibiotics in this situation?

Further specific prompts if needed

What questions would you ask?

Is this enough information to make a decision whether to prescribe antibiotics or would you like more information? *What extra information would you acquire in this situation?*

If enough information, what factors are driving this decision?

Why would you prescribe? Why is this? What makes you feel you have sufficient information at this point?

What are your thoughts relating to her medical history?

Could you elaborate on this a little? What do you mean by that? In what way is that important?

What would you look for on examination that would be important?

Answers to questions if specifically asked:

Off her food for the last day but managing fluids, and is passing urine normally.

Temperatures measured at home up to 39 degrees

Older sister who has just started school has had a cold but not been this ill with it

No rash

Imms UTD incl flu

Lily is quite grizzly and subdued, preferring to sit on Mum's knee and not interested in the toys in the corner.

Appears miserable, but pink and well-perfused

Temperature of 38.4°C

No signs of respiratory distress

Chest exam - good air entry with lots of upper airway noise but no crackles

ENT: Heavy green nasal discharge but no obvious focus of infection on ENT examination

Further specific themes/prompts if needed

Would you give antibiotics? Which ones?

How would you manage this case? What would you advise the parent?

What would make you more or less likely to prescribe antibiotics?

Why would X tip it for you?

Are there any specific cases or experiences that you think have influenced your current practice?

Any scoring systems, tools or guidelines used in helping make decision?

What do you think is causing Lily's infection?

Is immunisation status important e.g. whether she's had a flu jab?

What about the role of the parent in decision-making process? Give out any information leaflets?

Choice of antibiotic and duration?

Delayed prescribing strategy?

Gut feeling?

Importance of social factors? Parental pressure?

Specific safety-netting advice to give?

Would you bring her back for review?

How would this impact your decision making process?

How about a hospital referral – any thoughts on that?

I'd like to move on now to talk a little bit about a trial we're starting soon. But first of all, do you have any comments about this case before we move on?

Discussion of trial

I'd now like to tell you about a trial we're starting soon. There is evidence that there is a specific interaction between influenza and secondary bacterial infections, including Staphylococcal infections. We want to find out whether giving antibiotics to at risk children early in the course of flu-like illness can help prevent complications, to help inform management in the flu season and also in flu pandemics. The trial will involve randomising at-risk children who present in the flu season with cough and temperature above 37.8 to receive either co-amoxiclav or placebo and following them up to see if it makes any difference to re-consultations due to deterioration, duration of fever or duration of symptoms.

If it showed a benefit of giving antibiotics to at-risk children, how would this affect your practice?

Further specific prompts if needed

How would you feel prescribing antibiotics to a child you thought might have influenza? Any concerns?

What are your thoughts about their consulting behaviour in future?

Would you worry about increasing antibiotic resistance?

Which antibiotic would you choose to prescribe?

What other factors would facilitate/prevent a change in practice? Any ideas about overcoming these?

Would you want to see a particular degree of benefit e.g. NNT?

What extra information would you like to know to implement the findings? E.g. any criteria for how unwell the child should be, risk scoring system, etc

How much do you use evidence in explaining options with patients?

Be ready for a question about choice of co-amoxiclav: We chose this antibiotic because it's likely to be the antibiotic of choice in a flu pandemic and we wanted our results to be applicable to this.

Conclude and offer to answer questions

Discussion of current guidance e.g. NICE guidance for respiratory tract infections if desired. Ask if anything to add to bring to my knowledge.

Snowballing

Potentially ask them if they know of any colleagues who might be willing to participate in the study and ask for details/my details to be passed on.

If running out of time, offer to end interview, before talking about trial.

GP Regional Demographics

GP

number Primary Care Trust in which working at time of interview

- 1 Hampshire
- 2 Bristol
- 3 Bristol
- 4 Luton
- 5 Bristol
- 6 Northern Ireland
- 7 Oxfordshire
- 8 Hampshire
- 9 Oxfordshire
- 10 South Birmingham
- 11 Oxfordshire
- 12 Oxfordshire
- 13 Liverpool
- 14 Oxfordshire
- 15 Gloucestershire
- 16 Newcastle
- 17 Sandwell
- 18 Warwickshire
- 19 Liverpool
- 20 Hampshire
- 21 Tower Hamlets
- 22 Bournemouth and Poole

- 23 Bristol
- 24 Lewisham
- 25 Sunderland Teaching
- 26 Northumberland
- 27 Derbyshire
- 28 Trafford
- 29 Bolton
- 30 Wiltshire
- 31 Birmingham Crosscity
- 32 Sandwell and West Birmingham
- 33 Wakefield
- 34 South Derbyshire
- 35 Birmingham Crosscity
- 36 Birmingham Crosscity
- 37 Wigan Borough
- 38 Sandwell and West Birmingham
- 39 Birmingham Crosscity
- 40 Birmingham Crosscity
- 41 Harrogate and Rural Districts