

Shaping Our Future Together

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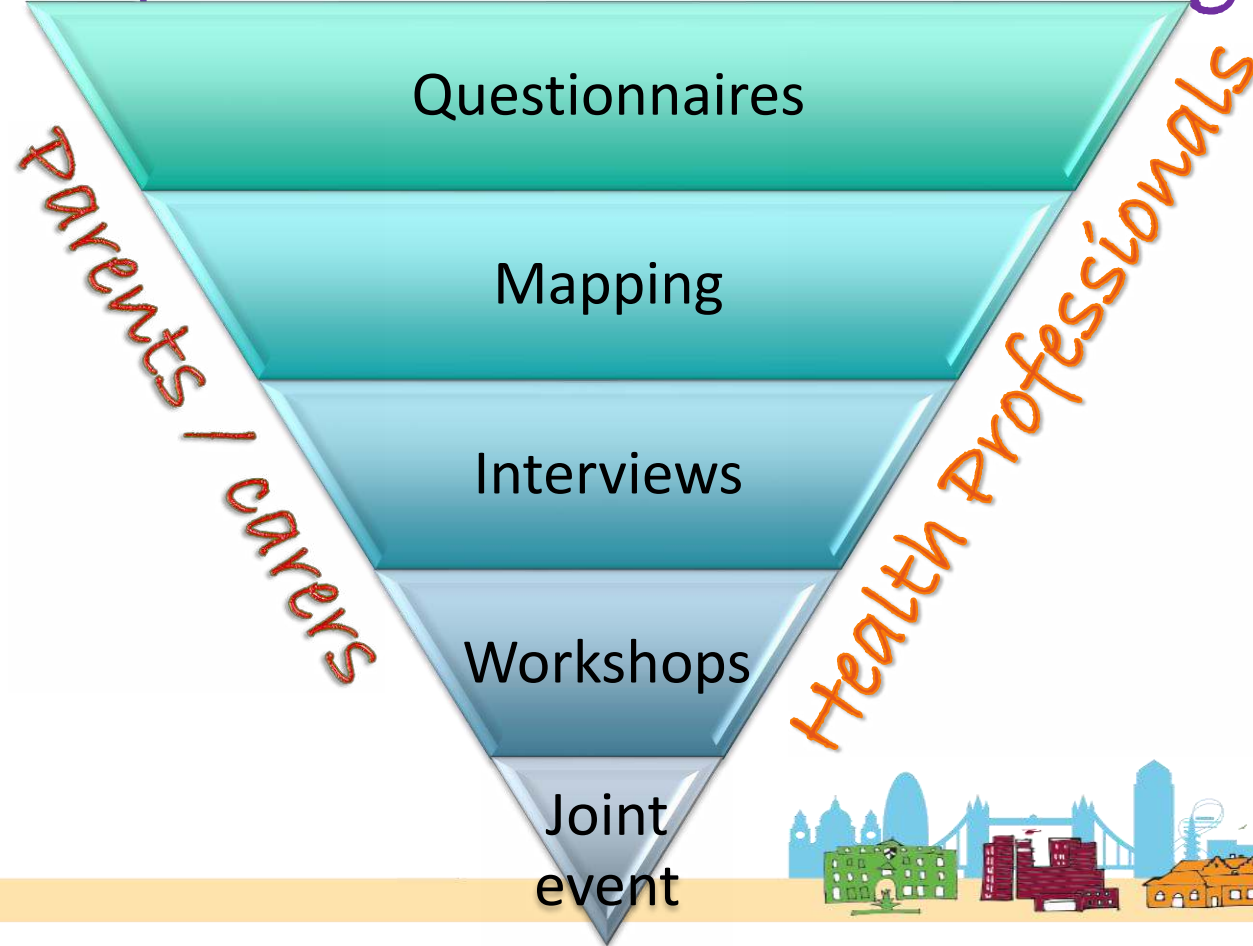


Background

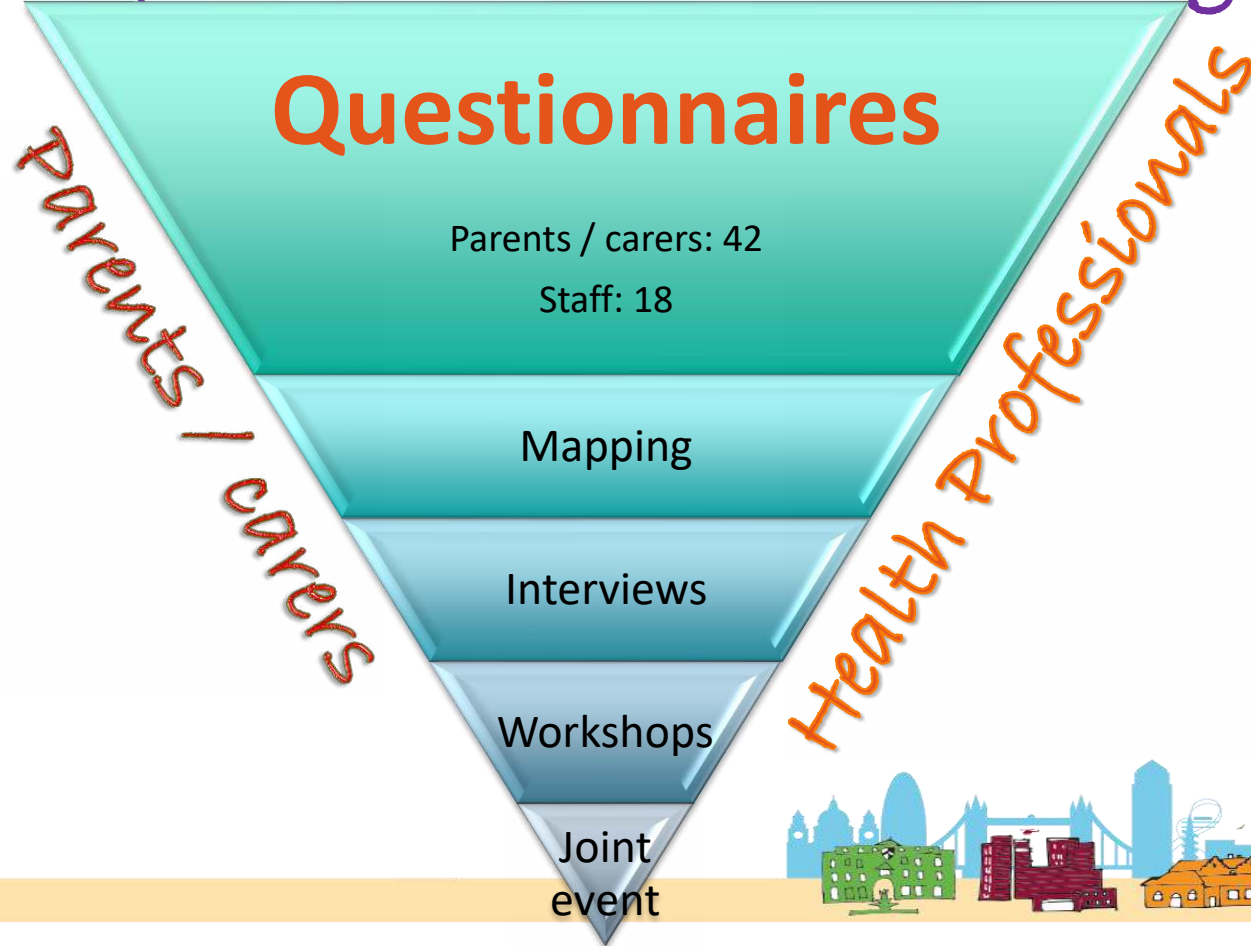
- ❖ Parents and carers of children with disabilities are twice as likely than other parents to provide care for more than 100 hours per week ('Caring More than Most', Contact, 2019).
- ❖ This group of parents and carers are more likely to have a low income, feel they have a poor quality of life with restricted social and life choices and have problems with their own health ('Caring More than Most', Contact, 2019).
- ❖ Tower Hamlets had the fastest growing population of any Local Authority in the country between 2001 and 2011 with a 29% increase in the number of households during this time (Census data, 2011).
- ❖ The census found that approximately 1 in every 25 CYP under the age of 20 years has a disability. The population of CYP in Tower Hamlets in 2017 was estimated to be around 75,500. It is therefore estimated that there are more than 3,000 CYP with a disability living in Tower Hamlets (Borough Profile 2018).



Experience-based co-design



Experience-based co-design



Acute Paediatric Therapies and Integrated Community Children's Service

Parent & Carer survey

My child is:

- 0-4 years 5-11 years 12-19 years

My child attends:

- Not in nursery / school yet Special School Mainstream Nursery / School
 Other (please specify): _____

Please tick the services involved with your child's care (MEH = Mile End Hospital / Community; RLH = Royal London Hospital / Acute)

<input type="checkbox"/> Routines-Based Early Intervention Team (PSP) - MEH	<input type="checkbox"/> Community Paediatricians (Child Development Team / Neuro-developmental Clinics) - MEH	<input type="checkbox"/> Community Children's Nursing Team - MEH
<input type="checkbox"/> Community Dietitians (tube feeding) - MEH	<input type="checkbox"/> Dietitians - RLH	<input type="checkbox"/> Continence Service
<input type="checkbox"/> Occupational Therapy - MEH	<input type="checkbox"/> Occupational Therapy - RLH	<input type="checkbox"/> Play Team - RLH
<input type="checkbox"/> Physiotherapy - MEH	<input type="checkbox"/> Physiotherapy - RLH	Other:
<input type="checkbox"/> Speech and Language Therapy (for communication) - MEH	<input type="checkbox"/> Children's Respiratory Physiotherapy Service (CCRPS) - RLH	
<input type="checkbox"/> Speech and Language Therapy (for feeding, eating and drinking) - MEH	<input type="checkbox"/> Speech and Language Therapy - RLH	

What do you appreciate most about the above services?

If you can change one thing about these services, what would you change?

What is the main difficulty you have when accessing these services?



Please circle your answer for each question:

1. People working with my child help me to feel like a good parent / carer.	Always	Mostly	Sometimes	Never
2. People working with my child care about my child and my family's wellbeing.	Always	Mostly	Sometimes	Never
3. People working with my child give me enough time to talk so I do not feel rushed.	Always	Mostly	Sometimes	Never
4. People working with my child listen to me when I talk.	Always	Mostly	Sometimes	Never
5. People working with my child ask me about my priorities and ambitions for my child.	Always	Mostly	Sometimes	Never
6. I feel like part of the team around my child.	Always	Mostly	Sometimes	Never
7. I find my appointments useful.	Always	Mostly	Sometimes	Never
8. It is easy to contact services involved in my child's care.	Always	Mostly	Sometimes	Never
9. Services share information about my child with each other so I do not have to keep repeating myself.	Always	Mostly	Sometimes	Never
10. Services provide us with enough information about our child's difficulties.	Always	Mostly	Sometimes	Never

Any other comments:

Thank you for your time ☺

Experience-based co-design



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Admission HUH

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Surgery OP
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Pain HUH
O&A ENT, Ophth, CDT

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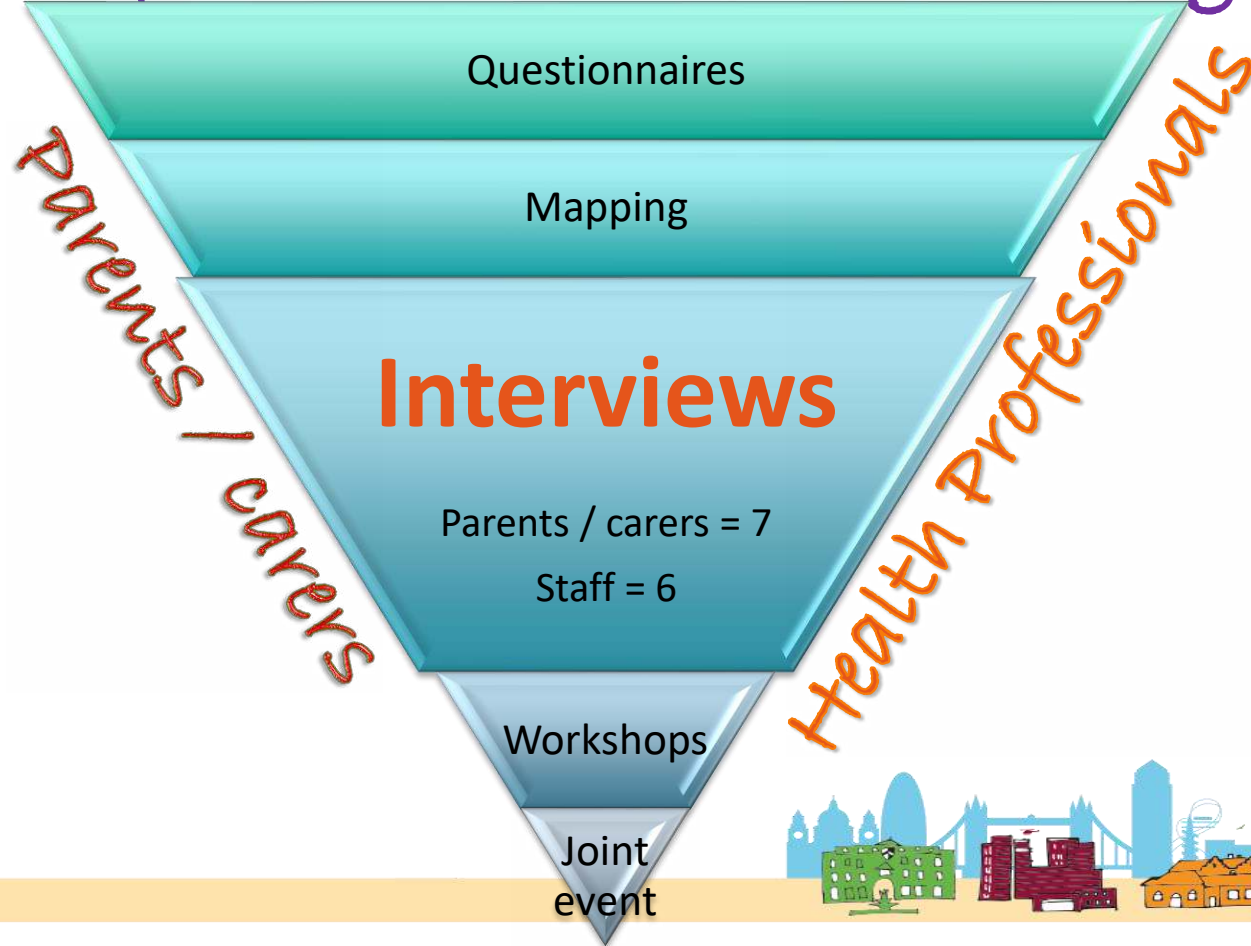
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Experience-based co-design





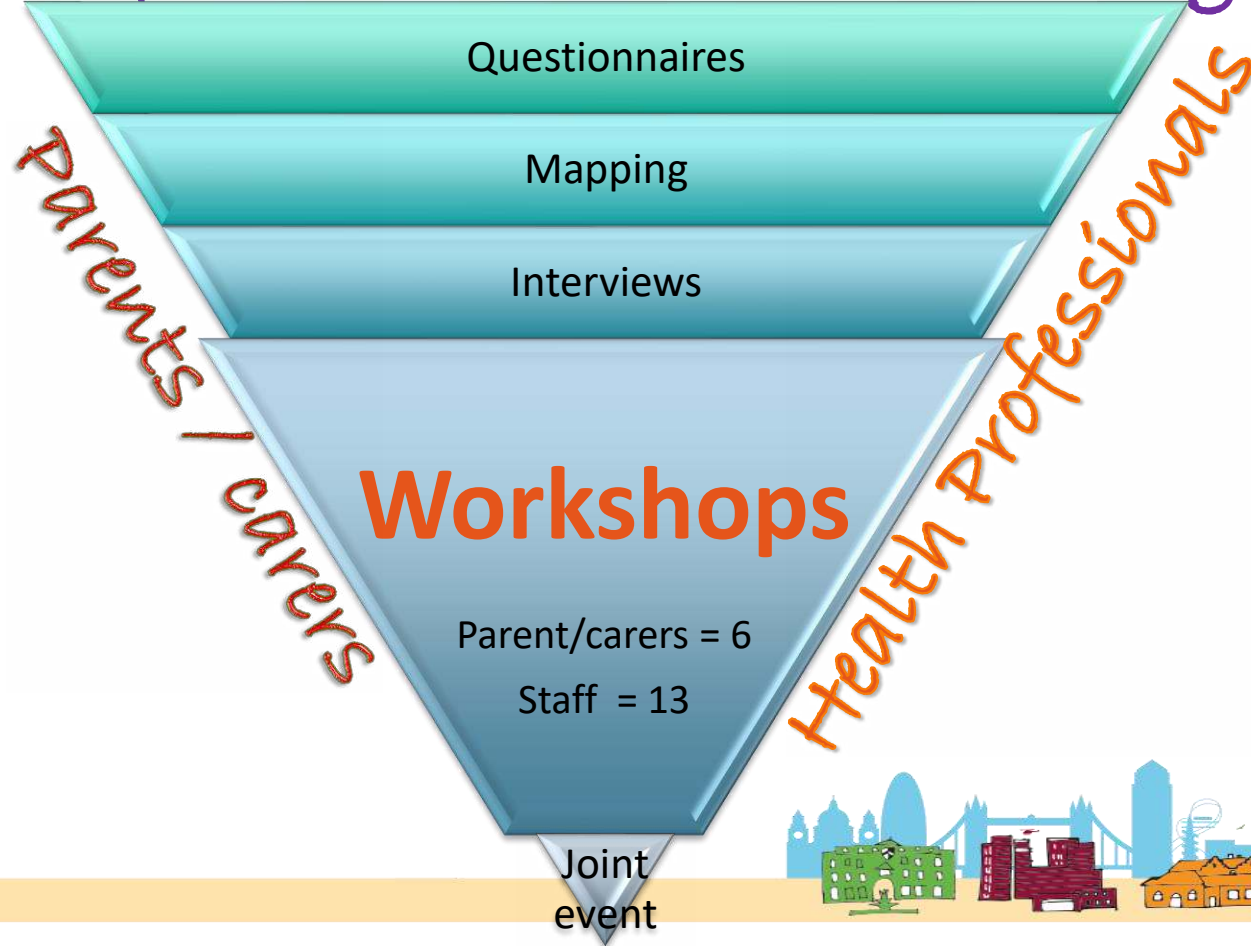
NHS

Barts Health

NHS Trust



Experience-based co-design





NHS

Barts Health

NHS Trust



Experience-based co-design



Outcomes identified at final workshop

By 2020 we would like to...

1. Have an established parent steering / volunteering group.
2. Have an updated Barts Children's Hospital website with relevant information including clear information and a directory of services such as medical, therapeutic, emotional and social support available as well as contact and referral details.
3. Have a clear standard operating procedure around contact with services i.e. 'duty' person, response times, contacting methods i.e. emails, team mobile phones
4. Have an improved appointment system where:
 - It is clear what the reason for appointment is (i.e. what is purpose of 'routine' appointment) and that there is clear reason for taking child out of school / education to attend the appointment.
 - There is a way of keeping in touch between appointments (i.e. skype, email, phone, "hot clinics"), especially to answer the questions that come up after appointments.
 - Clinic letters across services have a standard template for the plan, including:
 - When next appointment will be
 - Why / what for
 - Does child have to be present
 - Can it be done virtually / how else can aim of appointment be achieved
5. Implement a 'what matters to me' passport that is owned by parents / carers and used across all of children's services to share information.
6. Have a dedicated lead professional for every family.



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