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DOLPHIN EXERCISE PROGRAMME – CO-DESIGNING THE EXERCISE PROGRAMME

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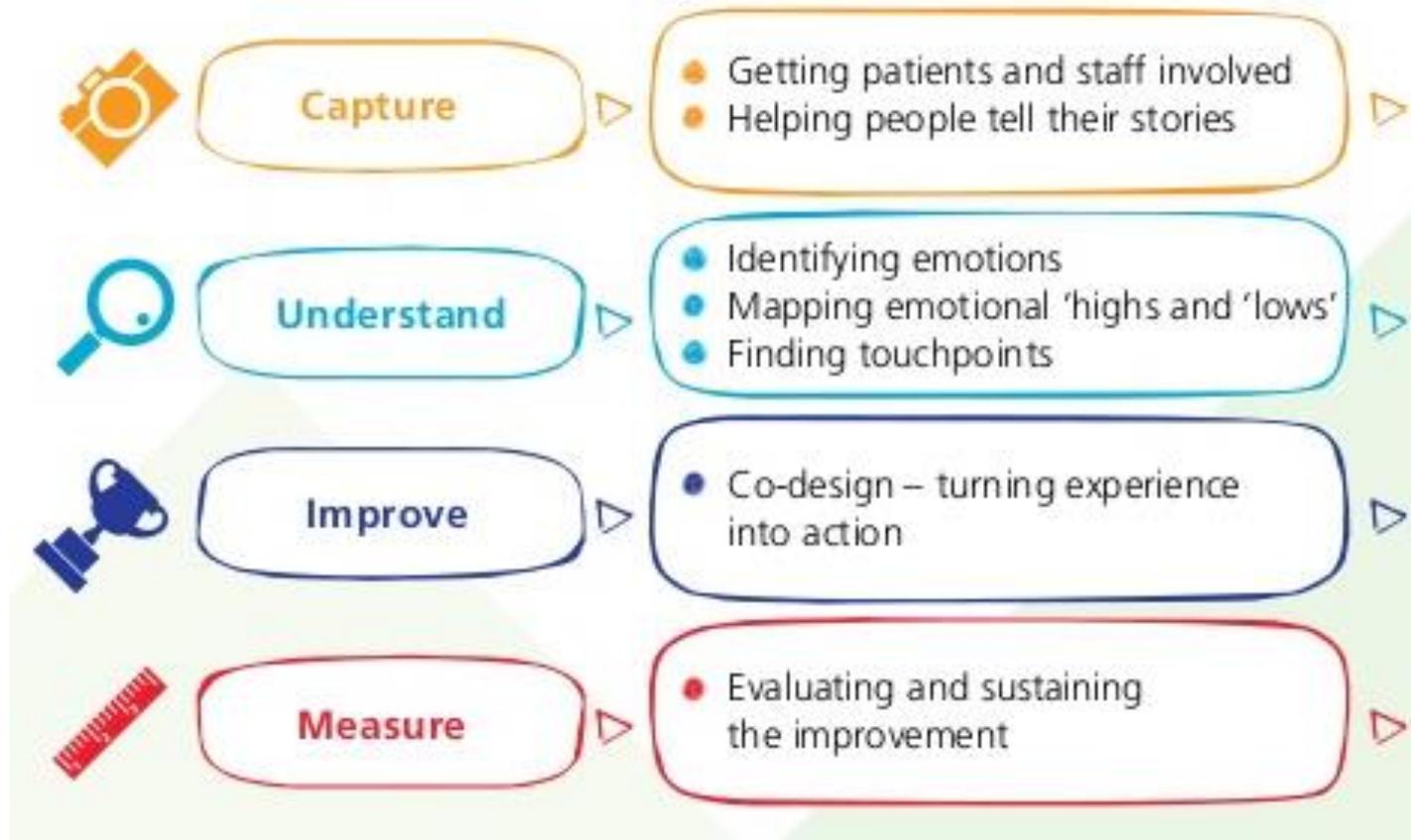
KEY ISSUES: RESEARCHING RARE DISEASES

Small-sized patient population

Limited validated outcome measures

Difficult to establish feasibility

CO-DESIGNING USING EXPERIENCE-BASED DESIGN PRINCIPLES



“co” suggests more of a partnership involving shared leadership between patients and healthcare staff, with the latter continuing to play a key role in service design. It does not involve making the patients design “experts”, but having the patients there involves them as “lead users” – rather than the leaders per se, as they have first-hand knowledge to expand and enrich a planned intervention

Bate and Robert (2006)

OBJECTIVES

Study 1: to engage children with haemophilia, their families and healthcare professionals to co-design a best-practice muscle strengthening exercise intervention aimed at improving musculoskeletal health by:

- Reviewing existing evidence from a systematic review of exercise and haemophilia and other randomised trials published since the review
- Exploring the perspectives of clinicians experienced in paediatric haemophilia care
- Exploring the perspectives of children with haemophilia and their families

Study 2: to re-evaluate the exercise programme and re-visit the intervention to amend any parts before progressing to a final trial by:

- Discussing and capturing feedback with the participants (children and parents) and the study's physiotherapists to identify any aspects requiring attention to help deliver the intervention for the larger study

OVERVIEW OF DATA COLLECTION & DATA SETS

Data source	Participants	Timeline of data collection	Type of data	Mode of collection
Review of literature	N/A	January to December 2016	Published literature	Evidence from literature review was synthesised and key findings extracted
Modified NGT and focus group	Healthcare professionals including academic physiotherapists (n=2), paediatric musculoskeletal physiotherapists (n=2), specialist haemophilia physiotherapists (n=7)	January 2017	Qualitative and quantitative data	Semi-structured discussion collected as focus group data; NGT self-completion questionnaire using a Likert scale
Focus group	Families including children (n=5), parents (n=5)	May 2017	Qualitative and quantitative data	Semi-structured discussion collected as focus group data; Likert scale self-completion questionnaire
Interview data	Children (n=9), parents (n=9)	October 2018 to April 2019	Qualitative data	Semi-structured discussion collected via one-to-one interview
Interview data	Study physiotherapists (n=2)	March and April 2019	Qualitative data	Semi-structured discussion collected via one-to-one interview

MODIFIED NGT / FOCUS GROUP?

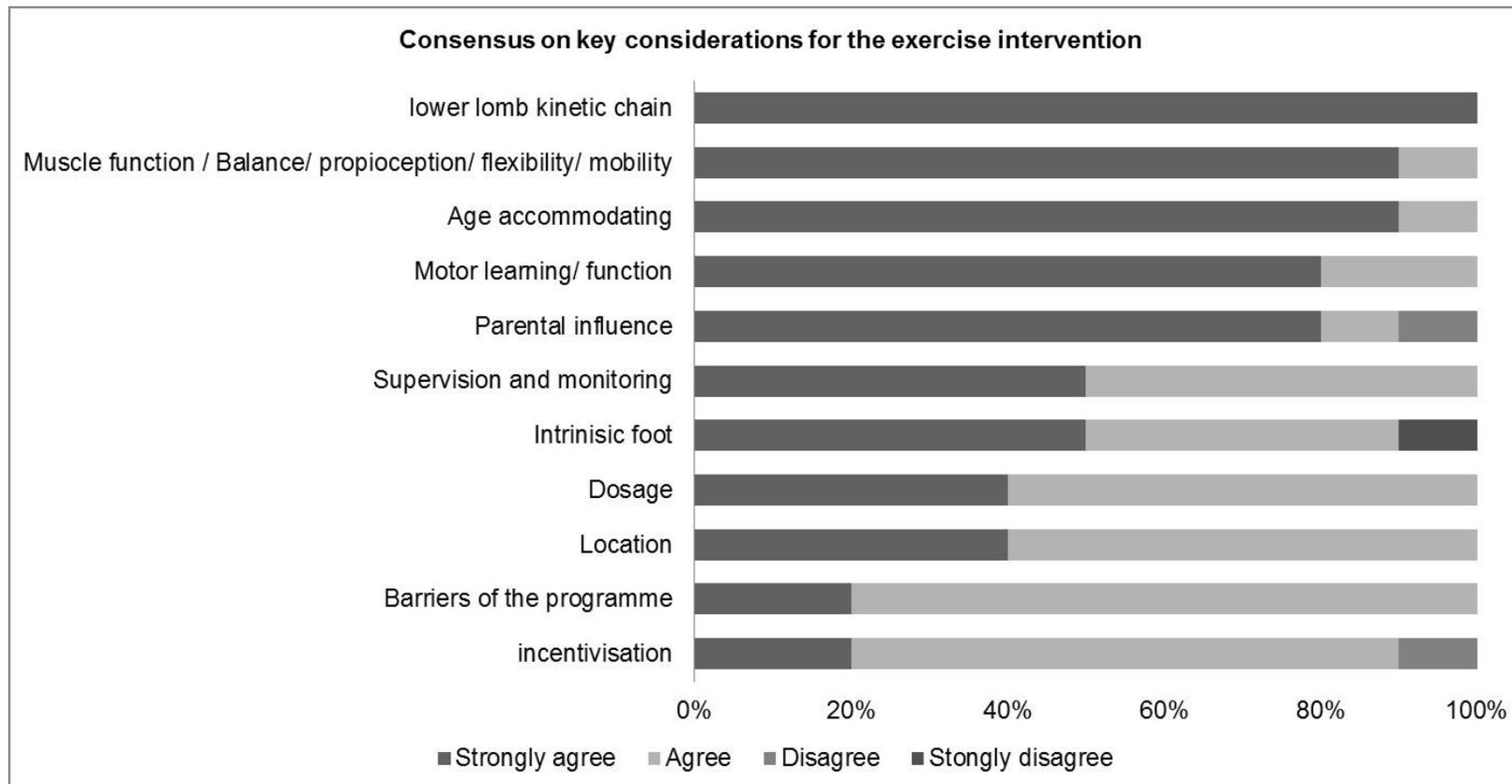
A modified nominal group technique (NGT) / focus group was utilised to facilitate the discussion and involved five stages:



STUDY 1: HEALTHCARE PROFESSIONALS IN MODIFIED NGT /FOCUS GROUP

Participant	Expertise
1	Academic physiotherapist
2	Academic physiotherapist
3	Paediatric musculoskeletal physiotherapist
4	Paediatric musculoskeletal physiotherapist
5	Specialist haemophilia physiotherapist
6	Specialist haemophilia physiotherapist
7	Specialist haemophilia physiotherapist
8	Specialist haemophilia physiotherapist
9	Specialist haemophilia physiotherapist
10	Specialist haemophilia physiotherapist
11	Specialist haemophilia physiotherapist

BAR CHART SHOWING PER CENT RATING OF KEY STATEMENTS BY HEALTHCARE PROFESSIONALS FOR MODIFIED NGT LIKERT SCALE QUESTIONNAIRE



STUDY 1: FOCUS GROUP WITH FAMILIES

Age	Participant	Parents present
6	1	1: mother
8	2	(as above)
7	3	1: mother
6	4	1: mother
10	5	2: mother and father
Subtotal	5 children	5 parents

FINDINGS

Theme	Statement
Theme 1: Preventing impairments related to musculoskeletal bleeding	<p><i>Yeah, particularly with the younger end because their feet are naturally pronated anyway and what you want to do is get them to gradually develop that long arch so it is...</i></p> <p>(Health care professionals – Modified NGT)</p>
Theme 2: Dosage	<p><i>I never hear of very many who do an activity five days a week. They usually do their activity maybe once or twice a week, whether it's their swimming or their football or their something.</i></p> <p>(Health care professional - Modified NGT)</p>
Theme 3: Age accommodating	<p><i>...there are different factors that might be important depending on their age so I think there is more than one way of splitting the age groups which would be a big thing to try and figure out for...You know, if they're growth spurting you might want a massive influence on stretching... but with a 6 to 10 year old you might want a huge impact on balance and control...</i></p> <p>(Health care professional – Modified NGT)</p>

FINDINGS

Theme	Statement
Theme 4: Location	<p><i>Parent: ...in the living room to do it quite easily I think so. If you set up a YouTube thing or like a DVD they've got something they can just turn on then follow...and then when they're done they're done. I know it sounds silly. Kids do follow technology like that these days.</i></p> <p>(Parent – focus group)</p>
Theme 5: Supervision and monitoring	<p><i>Parent: Also I think, I know because with the angle it's a bit strange so they need guidance for the beginning.</i></p> <p>(Parent – focus group)</p>
Theme 6: Incentivisation	<p><i>Parent: Sometimes a voucher does something...something like FIFA vouchers, you know all kids are going to be different I know.</i></p> <p>(Parent – focus group)</p>

STUDY 2: INTERVIEWS WITH CHILDREN AND PARENTS

Age	Participant	Parents present
11	Site A PI 01	1: mother
8	Site A PU 02	1: mother
11	Site A PI 03	1: mother
7	Site A PU 04	1: mother
12	Site A PU 05	1: mother
6	Site B PI 01	1: mother
10	Site B PU 02	1: mother
11	Site B PI 03	1: father
11	Site B PU 04	1: mother
Subtotal	9 children	9 parents

PI = Participant intervention group; PU = Participant usual care group

FINDINGS

Theme	Statement
Theme 1: Progression and adaptation	<p><i>Interviewer: And what didn't you like about the triangle stretch?</i> <i>Child: Well just hard to keep my back straight for when I did it.</i> <i>Mother: It was. But you...towards the end it was easier wasn't it, so...</i></p> <p>(Parent and child – Study Site 1)</p>
Theme 2: Maintaining adherence to the intervention	<p><i>Father: You had a few strops didn't you? You did end up actually doing them didn't you?</i> <i>Even if we split it down...did you find it easier when we split five exercises a day?</i></p> <p>(Parent and child – Study Site 2)</p>
Theme 3: Incentivisation	<p><i>Mother: It was yeah, but I mean we didn't know about the gift card until a couple of weeks after...</i></p> <p>(Parent – Study Site 1)</p>



SUMMARY

The co-design aspect of the project helped with:

- ❑ Understanding how to maximise adherence of the intervention
- ❑ Re-designing any elements of the programme that did not work in order to build a best practice model for the larger study
- ❑ Helping researchers to simply and effectively address any challenges posed with intervention delivery when working with children with rare diseases



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