Embedding Paediatric PPIE in Non-Invasive Ventilation Interface Design

1Nicki Barker, 1Heath Reed, 3Avril McCarthy, 3Kathy Jeays-Ward, 2Matt Willox, 4Pete Metherall, 1Heather Elphick*. 1Sheffield Children’s NHS Foundation Trust, Sheffield UK; 4Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, UK; 1NIHR Devices for Dignity MedTech Cooperative, Sheffield, UK; 3Sheffield Hallam University, Sheffield, UK.

Introduction
Non-invasive ventilation (NIV) masks that fit well are difficult to find for children who are small or have atypical facial features. Poorly fitted masks create problems e.g. discomfort, non-adherence and facial deformity. Our project aims to design and produce masks that fit well. Children’s voices are vital, but not often heard, in respiratory research projects.

Integral to the research, we aimed to construct a patient and public involvement and engagement (PPIE) program designed to:

1. Understand the problems children and families experience with NIV and establish their wants and needs
2. Provide an inclusive and creative environment for non-constrained thinking
3. Get actionable feedback and ideas for improvements from a diverse patient group

Method
We created a method focused on planning, innovation and participation (the PIP model). Session activities were designed to enable parents and children of all ages and abilities to participate. Examples include:

- Archery target activity – a method for realising the relative importance of patient’s requirement (prioritisation).
- Graphic scribe recording – to reflect back to the children that they had been heard/understood and stimulate creative ideas.
- Use of technology – making short videos to help families understand concepts.

Results
- Our priorities and design brief changed as a result of the PPIE.
- The graphic scribe outputs formed part of the creative process whilst providing a unique and lasting resource.
- We are confident that we will produce NIV interfaces that are fit for real life purpose that people will want to try.

Discussion
- For respiratory research to be truly successful, PPIE should be woven throughout a project, from concept to completion.
- It needs to be genuine and aligned with research aims.
- Time and effort spent enabling participation and creatively planning for inclusivity is rewarded by generating richer and more valuable information.

References