

Beyond Remuneration for Patient and Public Involvement Group Members

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Introduction

Respiratory infections are the main reason for hospital admission in preschool children and are associated with cold, damp housing. Childhood respiratory infections have lifelong consequences, increasing the risk of asthma and premature adult death. In Scotland, at least 1 in 5 households struggle to heat their homes. We do not yet know how many preschool respiratory infections could be prevented by tackling underheating.

The Homes, Heat and Healthy Kids study examines how children's homes affect their health.

We are proud to have established a new group of parents facing challenges heating their homes. The Parent Group brings together parents spanning the Outer Hebrides to the Borders and represents a number of minoritized ethnic communities and asylum seekers.

Methodology

We are using creative and inclusive methodologies to engage a group normally underrepresented in research and ensure their work is recognised in a way most meaningful to them.

The Parent Group meet regularly online at times which are suitable for them. We are mindful that they have care responsibilities (in addition to other life priorities) so we hold our meetings in the evening rather than during standard working hours.

The Parent Group are remunerated for their time using NIHR guidance, but we felt this did not adequately reflect their expertise and input.

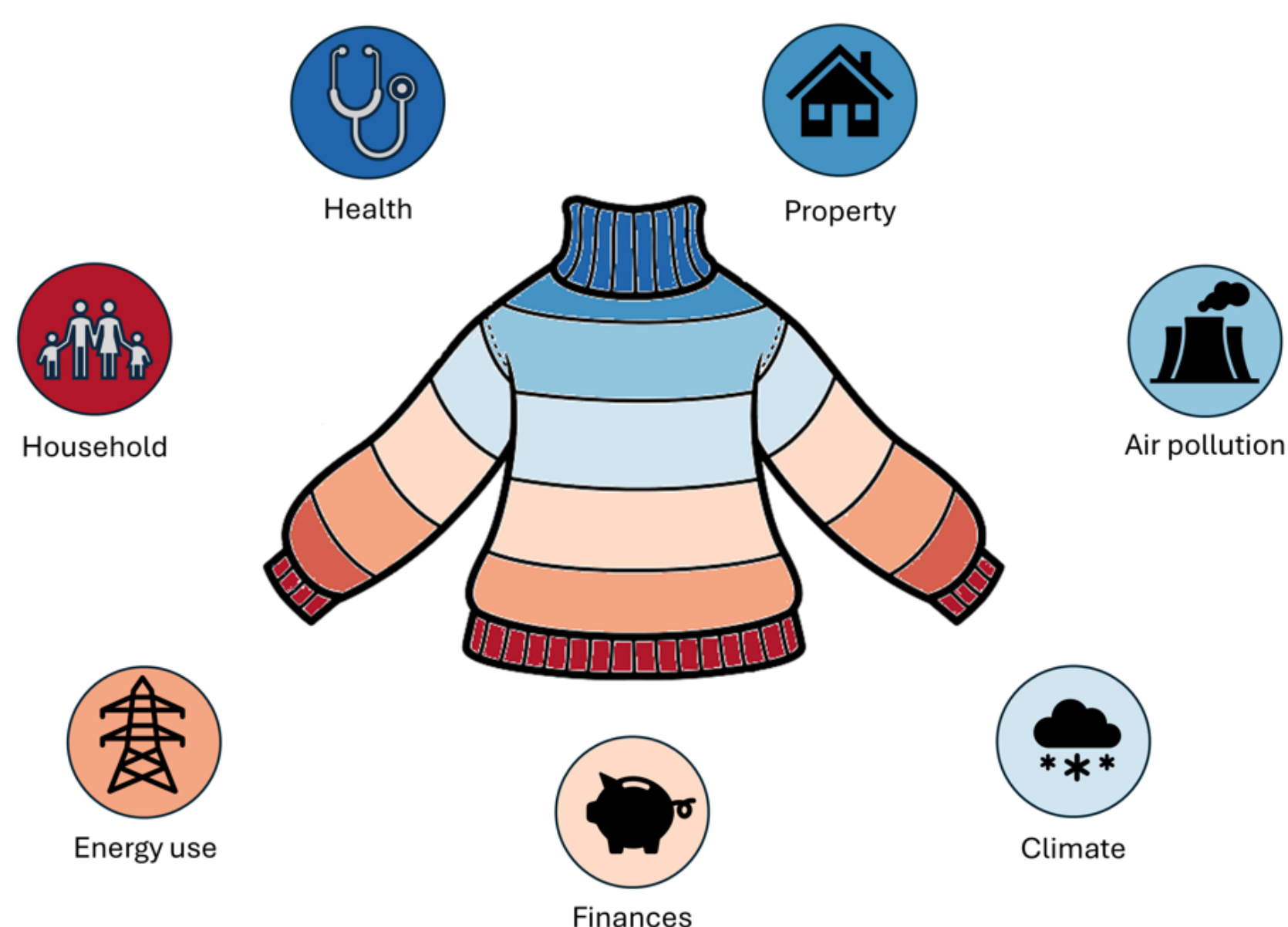


Figure 1: Project logo, codesigned with The Parent Group. Represents how many factors are “knitted” together to contribute to cold homes and childhood chest infections

Results

The Parent Group have co-designed the project from inception and co-produced a scientific animation to raise awareness of the link between cold homes and childhood chest infections.

Together, we discussed how to most meaningfully recognise their work. Many members expressed they have found it hard to gain qualifications due to financial or time barriers, and would value this as an outcome of being involved in the study.

The Parent Group have been working with Media Education to gain recognised qualifications for the work they have done. They have already attained a SCQF Level 3 qualification (Access to Media) and are working towards SCQF Level 5 Community Leadership qualification.



Figure 2: Animation, codesigned with The Parent Group.

Discussion

Impact for The Parent Group

- Establish themselves as local leaders for change.
- Establish themselves as local advocates for responsible research.
- Development of communication and presentation skills.
- Attainment of SCQF level 5 qualification to enhance career prospects.

Conclusion

Our work shows that working together with members of the public to decide how they would like to be remunerated for their contribution to research can produce innovative options with long-term benefits.



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Scan to find out more about our project and watch our animation

