

Trust and Confidence: Falling through the Gaps in the UK Rare Diseases Framework?

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Background

There are many specific challenges for those living with rare conditions which the UK Rare Diseases Framework¹ aims to address. This poster presents analyses from an extensive survey into the lived experiences of those who are affected by or care for someone with a rare, genetic or undiagnosed condition, run by Genetic Alliance UK in 2020 (in a partnership agreement with Alexion, Astra Zeneca Rare Disease Unit)^{2,3}.

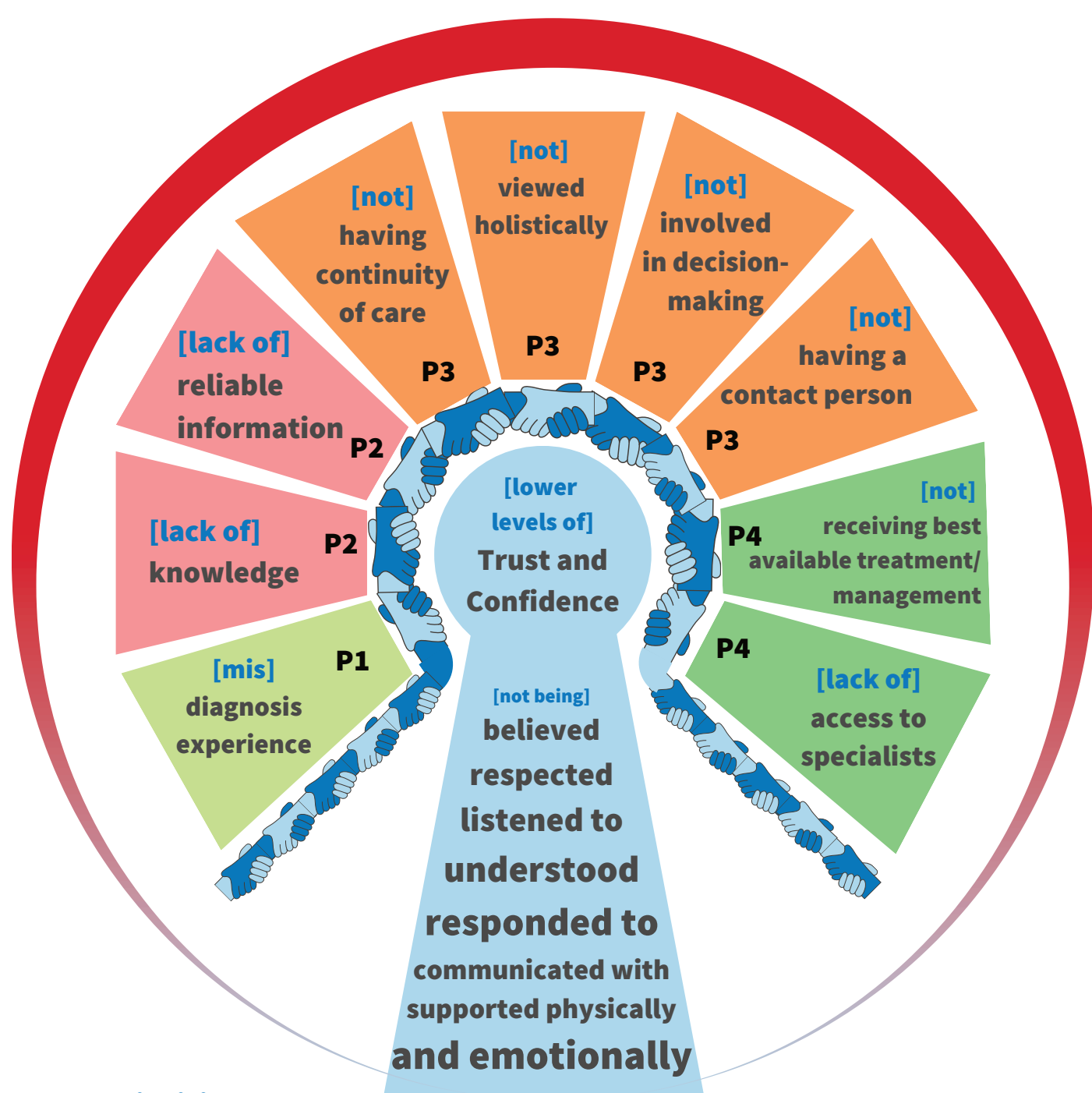
Methods

An online survey of 102 questions was live June to early August 2020, using SurveyMonkey. The survey used a mixture of closed questions with pre-defined response categories and questions that invited open-ended, qualitative responses; after exclusions the dataset consisted of 1,020 respondents. Roughly 300 different conditions were listed by respondents in the survey. People living with a condition made up 82% of the respondents while the other 18% were carers, most of whom (72%) cared for children under 18.

Quantitative Findings

Less than two thirds (59%) of respondents agreed or strongly agreed that they had Trust and Confidence in the hospital staff involved in ongoing care, compared with around a third (32%) agreeing with the same statement for GP practice staff and less than a third (30%) for paramedics and staff in emergency departments – see figure 1. This compares with over 80% of respondents to a cancer care survey in England saying they always had ‘Confidence and trust in all of the team looking after them in hospital’⁴. Trust and Confidence was shown to be significantly associated with someone’s overall care experience. The association was strong for Trust and Confidence in hospital staff, but weak for Trust and Confidence in emergency department staff and paramedics, and GP staff (though still a significant relationship).

Figure 2: How Trust and Confidence can be affected by experiences relating to the UK Rare Diseases Framework



Priorities

P1-helping patients get a final diagnosis faster

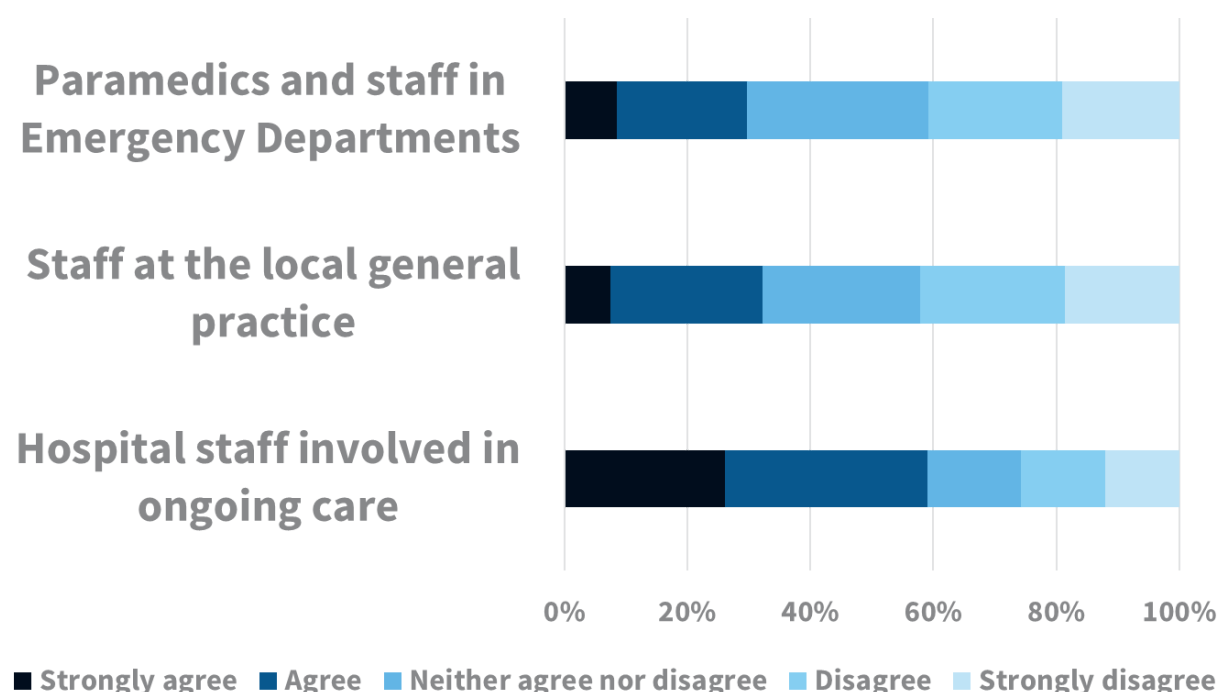
P2-increasing awareness of rare diseases among healthcare professionals

P3-better coordination of care

P4-improving access to specialist care, treatment and drugs

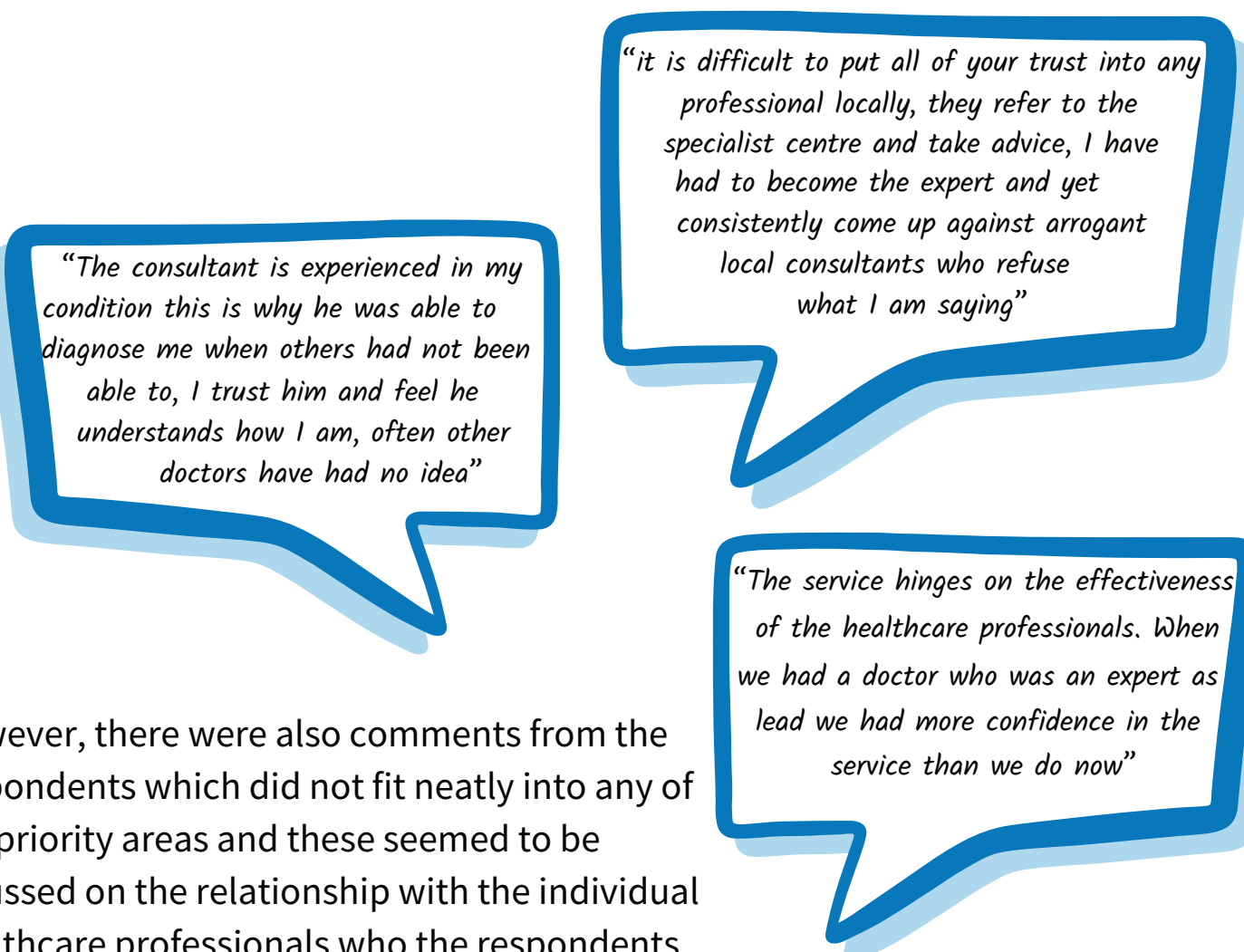
Figure 1: Confidence / trust in professionals treating

[To what extent do you agree with the following statement for each of the scenarios below: 'I have confidence and trust in the professionals treating me/the person I care for']



Qualitative Findings

Thematic analysis of the respondents’ comments indicated that Trust and Confidence was related to many healthcare experiences, especially how knowledgeable the healthcare professionals were – see example quotes below. People’s Trust and Confidence can be affected by their experiences in a variety of scenarios such as their journey to diagnosis and other themes apparent in the UK Rare Diseases Framework– see figure 2.



“The consultant is experienced in my condition this is why he was able to diagnose me when others had not been able to, I trust him and feel he understands how I am, often other doctors have had no idea”

“it is difficult to put all of your trust into any professional locally, they refer to the specialist centre and take advice, I have had to become the expert and yet consistently come up against arrogant local consultants who refuse what I am saying”

“The service hinges on the effectiveness of the healthcare professionals. When we had a doctor who was an expert as lead we had more confidence in the service than we do now”

However, there were also comments from the respondents which did not fit neatly into any of the priority areas and these seemed to be focussed on the relationship with the individual healthcare professionals who the respondents had contact with. These comments highlighted the importance of being believed, respected, understood, listened to, responded to, communicated with and supported both emotionally and physically to increase levels of Trust and Confidence – see figure 2.

Conclusions

It is possible that if there are improvements across all the priority areas in the framework then higher levels of Trust and Confidence in healthcare professionals may be observed but this may still miss some important aspects of Trust and Confidence such as the relationship with the individual healthcare professional.

Further research is required to fully understand the foundations of Trust and Confidence. As well as improving our understanding of Trust and Confidence from the view of patients, we also need to explore how prepared and confident professionals feel when encountering rare conditions for the first time. Only then can the necessary support for professionals be developed, to support the delivery of individualised high-quality care as set out in the framework.

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References

- 1 - Department of Health and Social Care. The UK Rare Diseases Framework. 2021.
- 2 - Genetic Alliance UK. Rare Experience 2020 The lived experiences of people affected by genetic, rare and undiagnosed conditions. Genetic Alliance UK; 2020.
- 3 - Alexion UK. Reforming Rare Diseases. Alexion UK; 2020.
- 4 - National Cancer Patient Experience Survey results 2022 <https://www.ncpes.co.uk/> [accessed Aug 2023]