

What trust and confidence in healthcare professionals means to those affected by rare conditions in the UK: exploratory analysis of a rare experience survey

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Background

Those affected by rare conditions face many specific challenges along their journey from the diagnostic odyssey to living with their rare conditions and coordinating complex care. Recent research has shown which challenges in combination have the most impact on overall care ratings; 'Trust and Confidence in healthcare professionals' was identified as one of the nine key variables¹. In order to better understand what Trust and Confidence in healthcare professionals means to those affected by rare conditions in the UK, we analysed data from an extensive survey 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 carried out in late June to early August 2020 using SurveyMonkey. The survey instrument 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. Statistics were used to find how strongly associated individual factors were with overall care ratings and then which combination of survey variables best explain overall care ratings given by the survey respondents (best fit model using multiple linear regression).

Figure 2: The nine factors which in combination best explained the overall care ratings given by the survey respondents

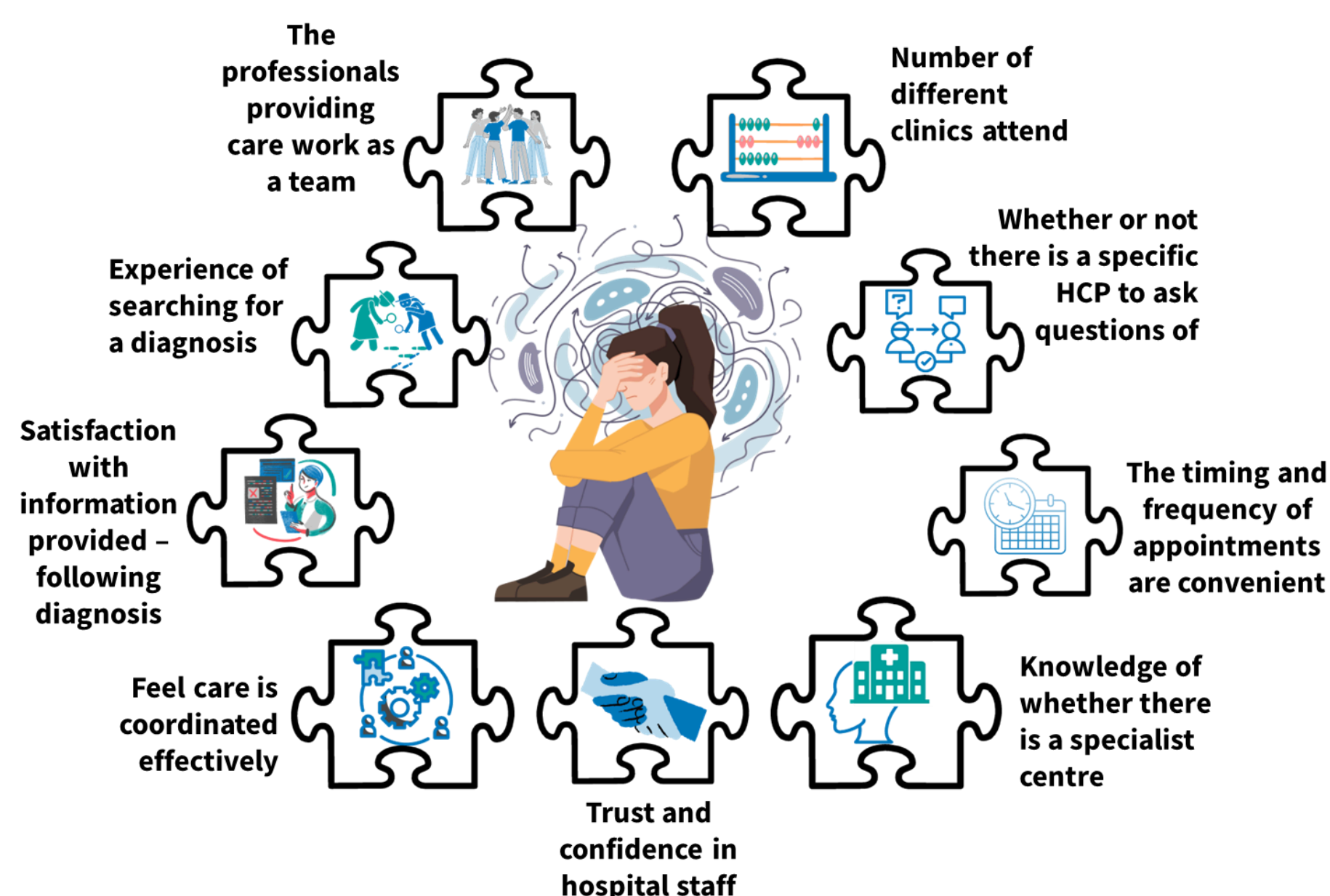
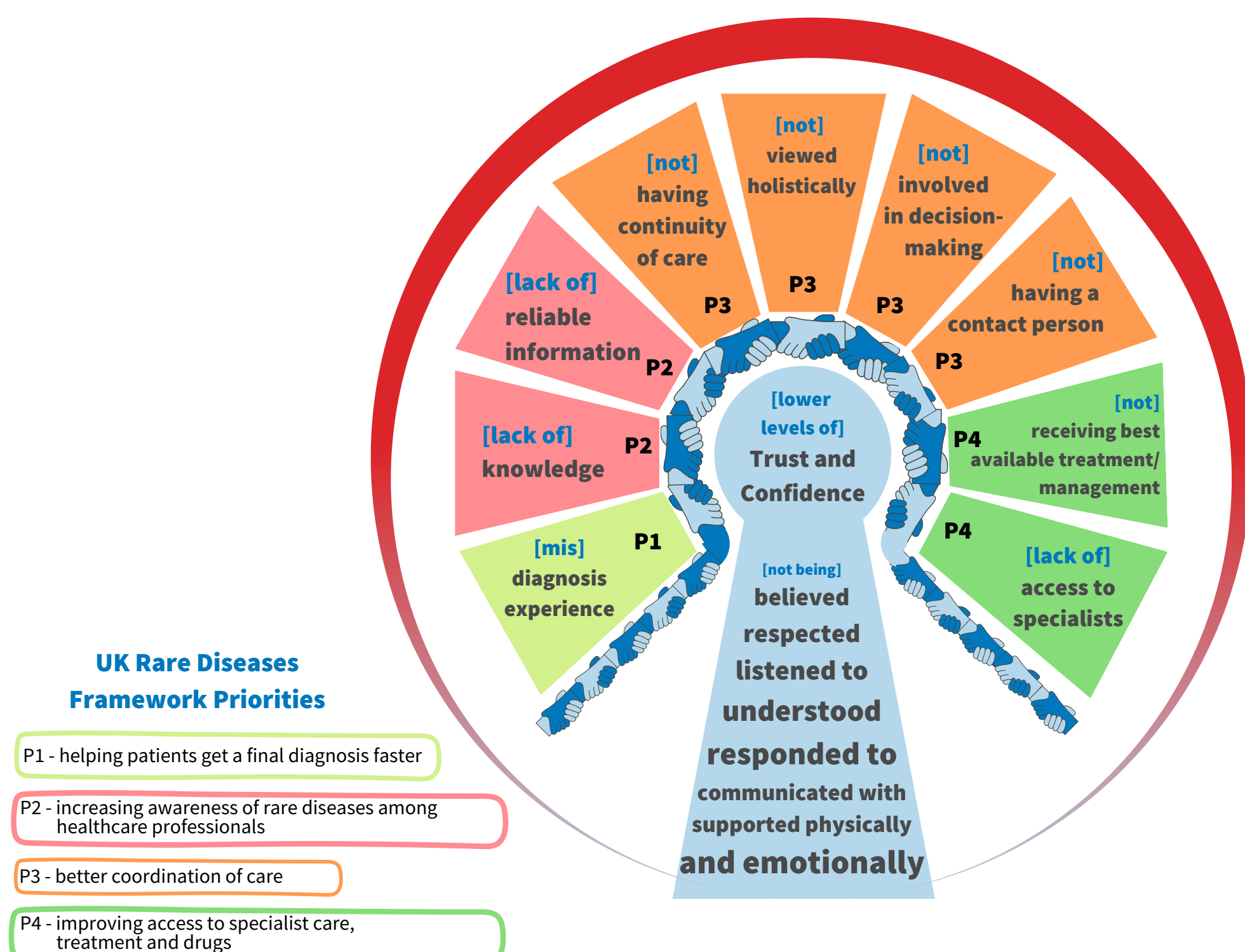


Figure 3: How Trust and Confidence can be affected by experiences relating to the UK Rare Diseases Framework

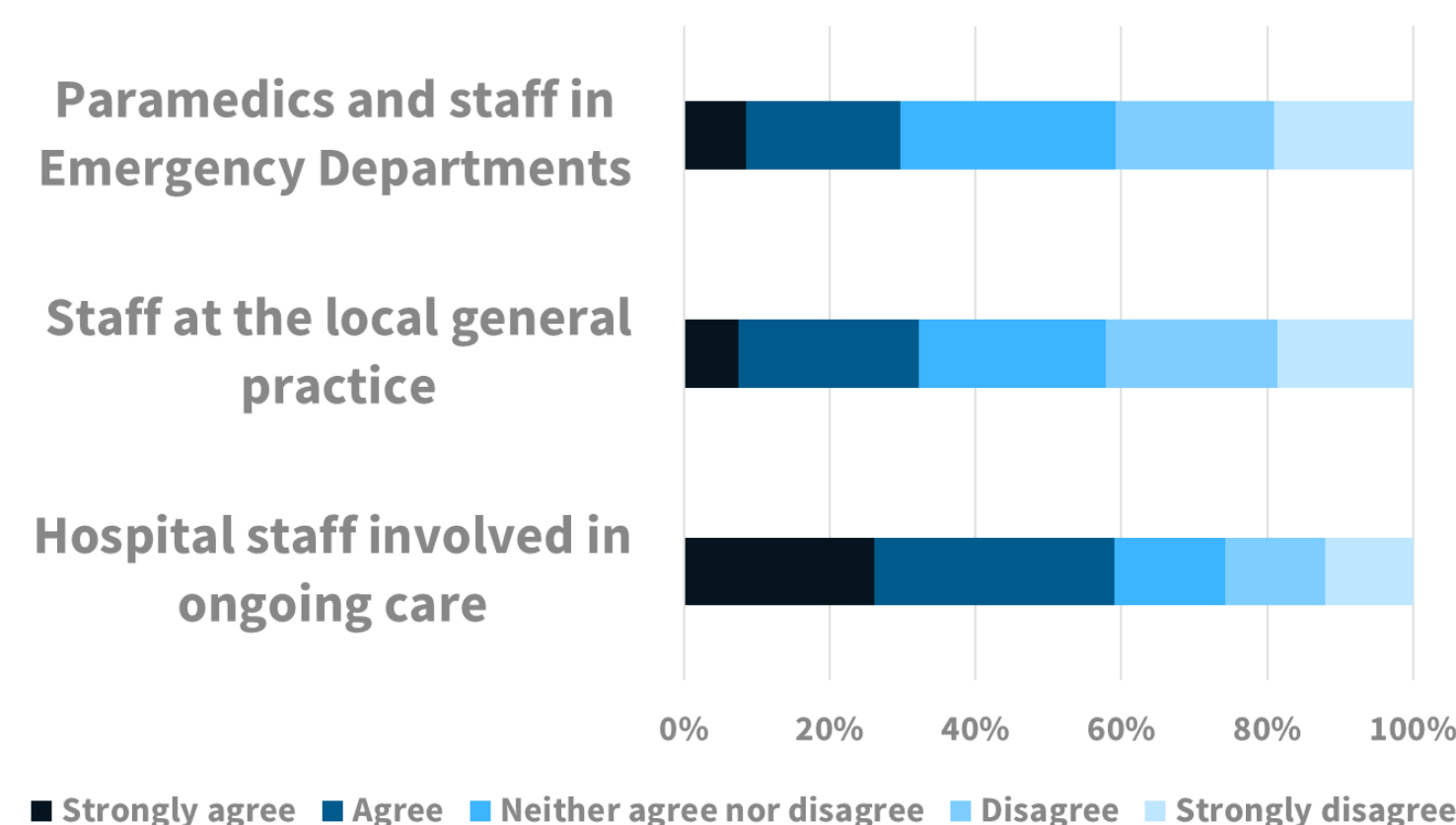


Quantitative Findings

Analysis from the quantitative elements of the survey showed that levels of Trust and Confidence in different groups of healthcare professionals varies. 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, around a third (32%) agreed / strongly agreed for staff at the local general practice. Less than a third (30%) agreed / strongly agreed for paramedics and staff in emergency departments – see figure 1. This compares with results of over 80% for respondents in a cancer care survey in England saying they always had 'Confidence and trust in all of the team looking after them in hospital'⁴.

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']



Trust and Confidence was shown to be significantly and positively 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 there was still a significant relationship). In the multiple linear regression only nine variables remained in the best fit model including Trust and Confidence in hospital staff involved in ongoing care – see figure 2.

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. Trust and Confidence did not correspond with just one priority area within the UK Rare Diseases Framework⁵, rather it could be interpreted as relevant across all areas – see figure 3.



However, there were also comments from the respondents which did not seem to 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 3.

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 and having to explain these to patients. Thereby establishing what support professionals feel they need to deliver individualised high-quality care for all those affected by rare conditions.

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References
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