

# Strategies for communicating with young people about clinical trial participation

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## Background

Limited improvements in survival in young people with bone cancer might be related to widely-reported low accrual to clinical trials. There are two important strands to effective information about clinical trial participation: 1) the clarity and accessibility of information given; 2) the quality of face-to-face communication. Together they facilitate shared decision-making<sup>1</sup>. Pearce and colleagues<sup>2</sup> describe the importance of forming trusting relationships between young people and health professionals to facilitate communication about participation in bone cancer clinical trials. Understanding strategies health professionals use to discuss clinical trial participation with young people with bone cancer, could yield recommendations for enhancing recruitment of young people to cancer clinical trials.

## Aim

We sought to explore strategies described by health professionals that promote trusting relationships when communicating with young people regarding participation in two bone cancer clinical trials, EURAMOS-1 and Euro-Ewing's-99.

## Methods

This study used narrative inquiry. In-depth interviews conducted with eighteen health professionals between November 2011 and February 2012 at a supra regional bone and soft tissue sarcoma centre, which was also a teenage and young adult principal treatment centre. Thematic analysis of interview data was conducted independently by members of the research team (SP, VL, AB and FG). SP and VL re-checked coded transcripts of all interviews to ensure no findings had been missed and data sufficiency had been achieved. Themes that emerged about strategies used to discuss clinical trial participation with young people with bone cancer, are shown below.

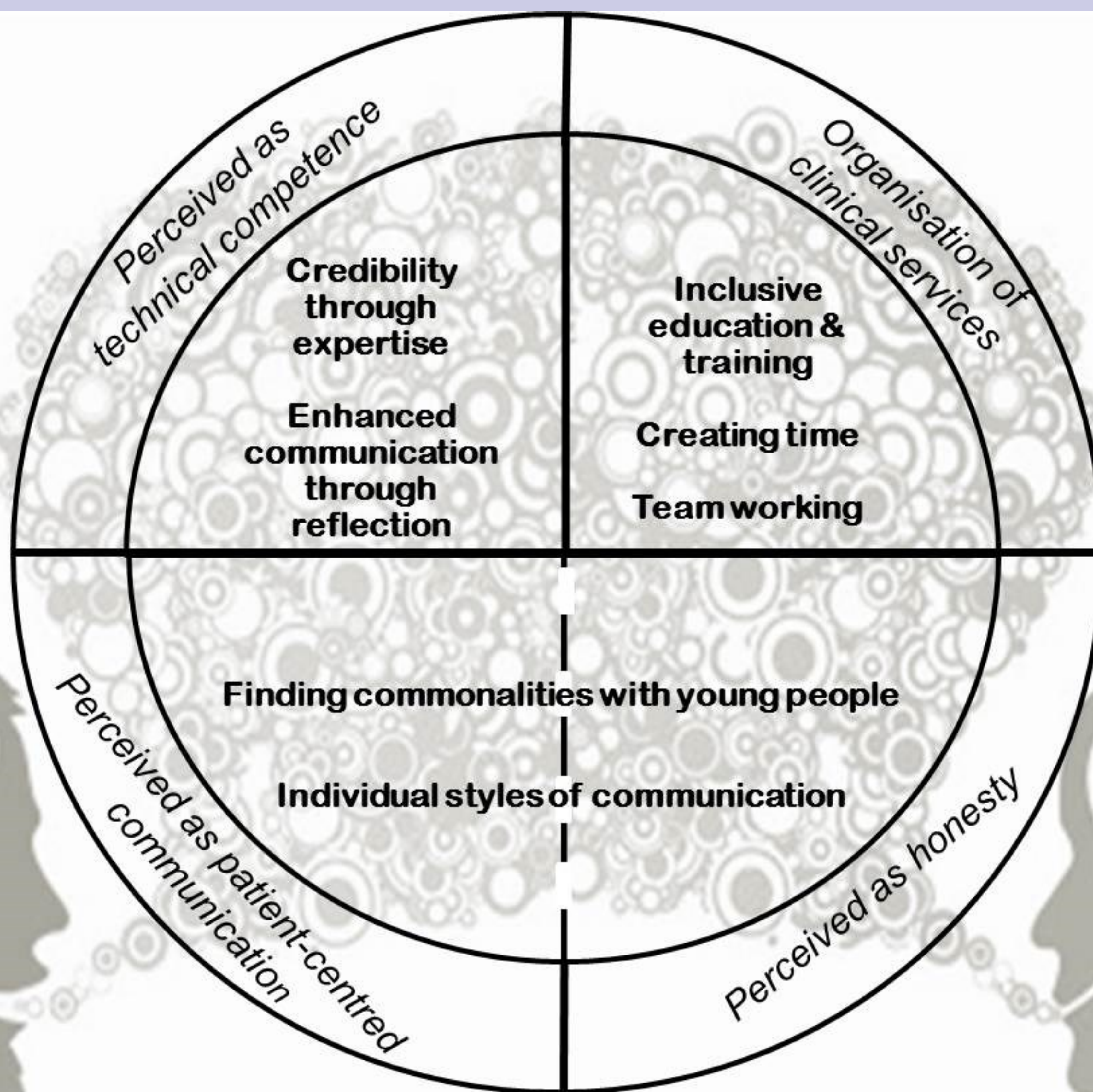
## Results

Findings from our thematic analysis aligned with the four characteristics of patient-physician trust<sup>3</sup>, which we mapped onto a diagrammatic framework (Figure 1). **Emergent themes** are shown in the inner circle of the framework (bold font below). Hillen and colleagues<sup>3</sup> *four characteristics of patient-physician trust* (italic font below) are shown in the outer circle of the framework.

Figure 1

Strategies that demonstrated the characteristic of *technical competence* included **having credibility through expertise of the team** and **developing communication skills through reflection**.

Strategies, such as **finding commonalities with the young people**, involved spending time to become acquainted and get to know the young person, even if that happened in a 'snapshot' of time.



*Organisational strategies* used were **inclusive approaches to education and training, making time to develop trusting relationships and effective team working**.

*Individual styles* of open and *honest, patient-centred communication* were used to identify commonalities and foster trusting relationships.

## Conclusions

- This study provides insight into strategies used by health professionals to build trusting patient-professional relationships to communicate with young people about bone cancer clinical trial participation
- Our findings have the scope to be transferred to other contexts of clinical trial recruitment to enhance effective communication as part of the trial recruitment and enrolment process.

## References

1. Nuffield Council on Bioethics (2015) *Children and Clinical Research: Ethical issues*, Nuffield Council on Bioethics, London, UK. pp. 131 - 175.
2. Pearce, S., Brownsdon, A., Fern, L., Gibson, F., Whelan, J. and Lavender, V. (2016) The perceptions of teenagers, young adults and professionals in the participation of bone cancer clinical trials, *European Journal of Cancer Care*, DOI: 10.1111/ecc.12476
3. Hillen, M.A., de Haes, H.C.J.M., and Smets, E.M.A. (2011) Cancer patients' trust in their physician—a review. *Psycho-Oncology*, 20: 227–241 DOI: 10.1002/pon.1745

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