twice in the previous week. Burnout symptoms (aMBI): 44% reported emotional exhaustion at a high level; 17% reported a high level of depersonalization.

The 25% of staff considering leaving PICU reported higher burnout (emotional exhaustion) scores (p=0.001); higher posttraumatic stress scores (p=0.04) and were also less likely to feel supported in relation to moral distress (p=0.010).

Conclusions These findings highlight the impact of changing PICU outcomes on staff, with increased survival of children with severe disability or technologically-dependent; and death following prolonged PICU admission sometimes after disagreements about cessation of LST, occasionally with public campaigns. They illustrate that the dimension of moral distress is one which needs to be acknowledged, along with burnout and post-traumatic stress in intensive care. Pediatric Crit Care Med 2017;18:e267–e273.

REFERENCES

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YOUNG PEOPLE’S VIEWS ON ACCESSING AND USING PERSONAL RECORDS FOR RESEARCH PURPOSES
1R Mistry, 1,2M Emonts, 1,2R Agbeko, 2Young Person’s Advisory Group, 4L Wilson, 1M Walsh, 3EJ Lim. 1Paediatrics, Great North Children’s Hospital, Newcastle upon Tyne, UK; 2Institute of Cellular Medicine, University of Newcastle, Newcastle upon Tyne, UK; 2Young Person’s Advisory Group North East, Newcastle upon Tyne, UK; 4Connected Health Cities, Newcastle upon Tyne, UK.

Aim Modernisation of records, coupled with advances in informatics, is making analyses of electronic records an increasingly rich source for researchers to help form evidence-based policy and treatments.

We aimed to review the public’s views on health research from electronic records and databases, with a focus on children and young people (CYP).

Method

- A literature search on the public’s perceptions of research from health records, data linkage, and acceptability of different modes of consent.
- Two focus groups using semi-structured discussions, to explore young people’s perceptions of access to healthcare data, were held with our Young Person’s Advisory Group. YPAG consists of 30 12–17 year-olds from diverse socio-economic and ethnic backgrounds.

Results Published research is primarily in adults. There is widespread unawareness and misunderstanding of research using health records. The public wish to be informed when their data is used for research as a matter of courtesy and to allow control of their participation. Opt-in consent was preferred. Opt-out consent is deemed potentially acceptable, with some studies demonstrating increased acceptability when participation bias is explained. Only one study explored CYP’s views (17–19 year-olds). This broadly mirrored adults’ views, including attitudes towards opt-out consent. No studies were found involving younger adolescents.

Our focus groups highlighted young peoples’ strong sense of ownership of their data and desire to be informed.

Acceptability of access to data varies depending on exactly what is being used, by whom and for what purpose. A high degree of precision and flexibility in permission-granting was desired, alluding to dynamic consent. A distrust in the security of their data co-existed with a misunderstanding of the protection anonymization provides.

Conclusion CYP are clear in their desire for active engagement when it comes to using their data for research and show appreciation for balancing one’s privacy against the ‘greater good’ for society. Further work is needed to explore how best to inform CYP of data use, allow informed participation, tackle misconceptions and maximise their partnership in this type of research. This is required to increase researchers’ transparency and accountability with the public and maintain public trust in clinical research.