Transition Compass: What do AYAs and healthcare professionals want in a transition intervention?

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Background:

Chronic health conditions affect 40% of Australian children. Most of these children will survive into adulthood and will have to navigate the transition between paediatric and adult care. This transition period is associated with increased morbidity and mortality as adolescents and young adults (AYAs) disengage from care, decreasing quality of life and increasing emergency care. There are currently no national, scalable programs to support transition. This codesign study aims to inform the development of such an intervention. We aim to evaluate the preferences of stakeholders to ensure the intervention (1) meets their needs (2) is sustainable within the healthcare system and (3) is consumer-finalised.

Methods:

Participants included AYAs (18-25 years) who had completed transfer from paediatric to adult specialist care for any chronic illness; parents whose child had completed transition; paediatric and adult healthcare professionals (HCPs) involved in transition. Codesign methodology was used, with sessions held for each participant group. All sessions were transcribed verbatim and analysed using NVivo 14.

Results:

96 participants (17 AYA, 8 parent, 46 paediatric HCP, 25 adult HCP), representing 5 states, >10 illnesses, and 11 hospitals participated. Three major themes were identified: (1) barriers and facilitators to transition, including systemic barriers experienced by HCPs and personal barriers experienced by AYAs accessing adult care; (2) psychosocial and health literacy needs, including key topics needing further support and education post-transition; and (3) defining a successful transition, including the varied perspectives of all participant and illness groups.

Conclusions:

All stakeholders identified barriers, and there is a critical need for support interventions to be developed. While personalised management of complex cases is needed, universally, greater transition support is required. We recommend the development of a digital, cross-illness intervention supporting AYAs' psychosocial and health literacy needs within the first two years of transition to adult care.

Disclosure of Interest statement:

All authors recognise the need for transparency of disclosure of potential conflicts of interest, and we assert that there is no relationship with prior publications or presentations associated with this abstract.