Abstracts

The Big Welcome

The Big Welcome intends to provide the right information for young people about their health care and support well-being. One idea generated from the Youth Forum was to provide a tailored Adolescent Pack on arrival to hospital.

Methods

We created a pack which is offered to all young people over 13 years old, where developmentally appropriate, admitted to the ELCH. This includes practical items, entertainment items and health promotion and engagement information.

Data is collected on the number of packs handed out and using a QI approach feedback is taken from young people in real-time on the content of the pack and through staff observation of what is used/ left behind. This information is used to improve the pack through PDSA cycles.

We initially tested the packs in one ward area and the emergency department short-stay unit. We selected the acute admissions wards as this would provide the highest turnover of opportunity to distribute the pack. Our play specialist team took the lead in distribution and collecting feedback. The pilot is funded by a charity grant, reviewed quarterly.

Results

We distributed 60 packs from May 2021 – May 2022 and received mixed feedback from young people. Some appreciate the gesture and some of the content, others have been disinterested/declined them or rated the content poorly. Feedback from the emergency department is that the packs are not tailored to short-stay and are more useful for those admitted to the main wards.

We have not been able to give out as many packs as planned (there are estimated X eligible young people per month admitted to the wards). Barriers identified are a lack of staff awareness of the project, core staff leave and admissions out of hours.

In response to feedback packs have been adapted to include QR code links to relevant health information about teenage sleep, sexual health and patient-led transition.

Conclusions

While the packs have been able to address some of the aims, they have not been as successful as hoped. We continue to evaluate the packs fitness for purpose and modify content in response to feedback. Our next step is to improve the distribution, then as part of the wider project to update information for young people on the ELCH website around transition planning and communication tools.

We have identified staff training is needed to improve comfort managing the needs of young people and content needs to be accessible.

The Big Welcome – Adolescent Packs: A Project to Welcome, Engage and Work with Young People Admitted to Hospital for Acute Clinical Care

Objectives

Young people admitted to our hospital often feel overlooked in their own care. Our aim is for all young people coming to our Trust to feel welcomed, informed and have developmentally appropriate care. With this in mind we piloted ‘The Big Welcome’ in the Evelina London Children’s Hospital (ELCH).

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We have identified staff training is needed to improve comfort managing the needs of young people and content needs to be accessible.
Methods Pre-and post-role implementation data were collected through discussion with, and evidence produced by, organisations on measures which include: evidence of transition lead roles for a whole organisation; number of organisations working through a transition Quality Improvement (QI) process; those with a transition contact; with Transition Executive Lead; QI transition pathways completed; health-based youth workers in post; processes in place to use feedback from young people on service improvements; effective transition governance processes e.g. transition board, steering group, organisational policy and reporting. Stakeholder groups included in the QI process include: hospitals (children’s and adult); community care; primary care; mental health; palliative and hospice care; and learning disability services.

An evaluation of this QI model for transition implementation is also underway, conducted by researchers at the University of Surrey, in collaboration with the Burdett National Transition Nursing Network. The National Transition Evaluation Study utilises a multi-centre concurrent mixed methods design, with qualitative (interviews/auto-ethnography/case studies), and quantitative descriptive (surveys) data collected simultaneously over three phases with: young people, parents, transition champions and key professionals involved in the young person’s transition journey.

Results Reporting on the two years since implementation, there has been an increase seen across all measures, confirming that the RNA role is having a positive impact on transition. Hospitals have engaged well with the QI process, but still transition work needs to be expanded across whole organisations, with sustainability plans needed. Developing a model of care for young people in primary care, those with learning disabilities and those receiving primary care mental health has been identified as a particular challenge, and will be a targeted focus in year three. Sharing knowledge, learning and tools through regional meeting and Community of Practice events has been invaluable, with up to 180 participants at each event.

Conclusions The QI process has provided structure and guidance. As an intervention, the RNA roles have influenced change over time. In this presentation, we will use data to illustrate where change has occurred and indicate what might have influenced that change. We will present our approach to evaluation, used to examine processes, to not only describe what has worked, but why, for who and in what context. This learning is essential to inform both practice, policy and future research.

Objectives Developing health literacy is a cornerstone of transitional care (TC) programs for young people (YP) living with long-term conditions. Lower rates of health literacy correspond with a decreased likelihood of appropriate, effective healthcare seeking behaviour and worse health outcomes. UK data has found that amongst people living with sickle cell disease (SCD), young adults have the highest rate of emergency hospital admission which are associated with increased risk of mortality.

Our objective was to comparatively assess health literacy and transition preparedness of YP with SCD at different time points of the TC journey with the experiences of YP living with other long-term conditions (type 1 diabetes & epilepsy). We also assessed the efficacy of a bespoke, digital health education tool at improving health literacy.

Methods Ready, Steady, Go (RSG) is a NICE endorsed TC program that addresses a full range of transition parameters at specific timepoints of the patient journey.

147 YP living with long-term conditions (SCD, epilepsy and diabetes) returned age-appropriate RSG questionnaires filled at different time points during their transition process. 4451 unique responses were collected to questions addressing the following areas:

- Knowledge and understanding of their condition
- Treatments
- The healthcare team
- Confident self-advocacy
- Adolescent health issues
- Educational, independence and vocational domains
- Psychosocial issues
- Concept of TC.

Our clinical experience using the RSG questionnaires had shown us that unanswered questions are informative indicators of ‘help’ in areas of need. We thus elected to include questions without a response a negative indicator in our evaluation.

In response to our data, a bespoke, animated SCD transition education package was developed (figure D) and offered to YP with SCD

Results Data analysis found that at all stages of transition, YP with SCD (n=42) were less likely to report confidence in transition parameters compared to YP living with other conditions (n=105) (figure A). The difference was most pronounced in domains assessing understanding and self-administration of medication (79.9% SCD vs 89.9% other conditions). There were low reported rates of requesting and collection of repeat prescriptions (13.9% SCD vs 47.4%) (figure B). YP with SCD reported lower rates of resilience in managing bullying (26.1% vs 3.5%) and were less likely ‘feel happy with life’ (73.8% vs 86.4%) (figure C). YP with SCD were less confident in disclosing their condition to others (36.8% vs 11.8%). Regarding social support, 24% of respondents with SCD said they did not ‘know someone I can talk to when I feel sad or fed up’ vs 8.3% of YP with diabetes and were less likely to see friends outside of school.

The digital SCD educational tool was effective, demonstrating an uplift in confidence and understanding parameters from 47.8% to 84.6% after YP used the resource (figure E).

Conclusions Our data demonstrates a significant health literacy gap in YP with SCD transitioning to adult care that is larger than that seen in YP living with other long-term conditions. Targeted digital health education interventions are effective at helping to boost health literacy, engagement and confidence and should be incorporated into TC programming.