Paediatric Clinical Leaders: Service Planning, Provision and Best Practice

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INCORPORATING THE VOICE OF THE CHILD: FEEDBACK FROM LOOKED AFTER CHILDREN ON CHANGES TO COMMUNITY PAEDIATRIC SERVICES DURING THE COVID-19 PANDEMIC

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Background The Covid-19 pandemic and resultant requirement for social distancing has necessitated changes to many Children's and Young People's (CYP) Services. There has been widespread concern amongst health and social care professionals about how these changes may be impacting vulnerable CYP, especially Looked After Children (LAC). A community child health centre in East London moved to a predominantly remote format of health assessments for LAC during the Spring 2020 'lockdown'. The multi-agency partnership wanted to understand the views of service users and impact on CYP of the shift to predominantly remote interactions with the LAC medical and nursing team

Objectives To understand the service user perspective of 'Looked After Children' in an East London Borough during the COVID 19 pandemic, including views on virtual consultation. This was with a view to optimising the service for the future.

Methods The LAC Health team, in partnership with the local authority and Children in Care Council, conducted a virtual focus group with 'Looked After Children'. The CYP were members of the Children in Care Council and volunteered to participate. The age range of participants was 8 to 17 years. The group was conducted using the video-conferencing platform 'Zoom'. It was facilitated by paediatricians, nurses, and a patient participation lead. CYP were divided into break-out groups, and a virtual 'brainstorming' tool was also used. The participants were asked about where and how they access health information, how they prefer to interact with the healthcare team, and what they felt had been positive and negative about how their service has been adapted during the current pandemic, as well as their hopes for the future service. The session lasted 1 hour.

Results The following themes were extracted from the discussion:

- Most participants said their carer was their first port of call for health advice. Some participants also used technology such as search engines and apps for health queries.
- While most felt the paediatric team's main role was to look after their physical health, some also mentioned the importance of their human connection with the healthcare team.
- All the participants said that, given the choice, they would prefer to have 'face to face' appointments.
- Attitudes to telephone versus video appointments varied; some felt that being able to see their healthcare workers was very important to the interaction, but others found video calls uncomfortable. Poor internet access was mentioned as a barrier to using online video platforms for consultations.

Conclusions The wellbeing of vulnerable CYP has been of particular concern amongst health and social care workers during the Covid-19 pandemic in the UK. During the pandemic, our service has become more reliant on technology and virtual consultations. Of note, the young people we spoke with reinforced the importance they placed on face to face interaction where this is possible.

Service user feedback and co-development is vital to our attempts at optimising our services and ensuring the voice of the child continues to be heard, even during a pandemic. The department incorporated this focus group feedback and increased face to face consultations.

British Paediatric Allergy Immunity and Infection Group

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IMPACT OF THE COVID-19 PANDEMIC ON THE DELIVERY OF THE EUROPEAN THYMUS TRANSPLANTATION PROGRAMME

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Background Congenital athymia, due to complete DiGeorge syndrome (cDGS) or rare monogenic disorders affecting thymus development, is associated with profound T-cell lymphopenia and susceptibility to opportunistic infections. Left untreated, athymia is fatal within 1–2 years. It can be successfully treated by thymus transplantation, using cultured thymic tissue obtained from infant donors when necessarily removed during cardiac surgery. In Europe, thymus transplantation is only offered at our centre. Following increased awareness and progressive international implementation of newborn screening (NBS) for severe combined immunodeficiency (SCID), we received a record number of referrals in 2020. Significant restrictions on worldwide travel and reallocation of healthcare resources during the COVID-19 pandemic resulted in the temporary interruption of international admissions. In order to facilitate the timely admission for this life-saving treatment, we developed a modified care pathway (MCP) to address the challenges identified at local, national and international levels.

Objectives Optimisation of resource allocation to prevent negative impacts of delayed treatment in athymic infants during the COVID-19 pandemic.

Continued delivery of high quality, complex patient care and positive patient experience through a MCP.

Methods We conducted a service evaluation to assess the effectiveness of the MCP and the impact on time-to-admission for transplantation.

We completed short interviews with accompanying parents and referring clinicians to survey their experience of the thymus transplantation programme during the pandemic.

Results With the support of our Trust and NHS England, a MCP was agreed and implemented to ensure safe transfer, admission and repatriation.

We regularly amended our admission protocol to reflect the evolving local and national infection prevention control (IPC) policies. We gained adherence from all referring teams and families, while observing the local requirements of the referring teams in 6 European countries and New Zealand.

Due to the limited access to donor tissue, secondary to reduced elective cardiac surgery, admissions required optimised coordination between multidisciplinary teams to allow for thymus transplantation within 20 days of donor tissue collection and culture.

From May 2020 to March 2021, 10 patients underwent thymus transplantation, reflecting a 50% increase in activity on previous years. The average time for referral-admission was 5 months. 4 patients were identified by NBS in their respective countries and in line with current SCID management guidelines, 2 of them were transplanted by the age of 4 months. One patient tested positive for SARS-CoV2 on return to their home country and made a full recovery. This prompted further changes in our transfer guidance and local IPC practice.

Parental interviews highlighted anxieties around international travel, restricted hospital access for the second parent and non-aligned IPC practices in comparison with referring centres. Equally, they accepted and embraced the additional restrictions in order to access their child's essential and only, treatment option.

Conclusions Upon prompt identification of challenges and risks to treatment delay for athymic infants during the COVID-19 pandemic, we overcame them in collaboration with referring centres, multi-disciplinary hospital teams and the patient families, resulting in the successful delivery of a record number of thymus transplant procedures following a MCP, maximising the opportunity for improved long-term outcomes.

Quality Improvement and Patient Safety

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IMPROVEMENTS IN PAEDIATRIC DIABETES SERVICE USING KAIZEN – A PROCESS OF CONTINUOUS IMPROVEMENT USING LEAN TOOLS

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Background The Lean for Leaders is a 9-month training programme based on Kaizen methodology with the goal of developing skills and confidence of team leaders to use the 'lean' tools to transform health care. The aim is removing waste and using efficiency-based methods to deliver improvements in service.

Objectives To evaluate the impact of Kaizen, continuous improvement, in Paediatric Diabetes Unit (PDU) after Lead Clinician for Paediatric Diabetes completed the Lean for Leaders Programme.

Methods We are a Paediatric Diabetes (PDU) with 232 Children and Young People with Diabetes (CYPD).

We submit data annually to National Paediatric Diabetes Audit (NPDA) undertaken by Royal College of Paediatrics and Child Health (RCPCH).

Data submitted includes

1. HbA1c results for all patients
2. Health check completion of 7 key care processes: HbA1c, BMI, thyroid function, retinopathy screening, urine albumin creatinine ratio, blood pressure and foot examination for CYPD over 12 years.

To improve these performance indicators, we used Kaizen bases lean tools as below, without increase in staffing or PDU funding:

- Age specific education sessions at secondary school and university entry
- Diabetes Nurse led review for CYPD with suboptimal control between clinic appointments
- Negotiated availability of Flash Glucose Monitoring with local clinical commissioning group
- Designed and used an electronic proforma at annual review appointments for documenting and completing care processes
- Introduced pre-clinic multidisciplinary team huddle to enable focused consultation and problem solving with clear ownership of jobs arising
- Streamlined process for obtaining retinopathy screening results
- Use of 'live' improvements board. This kept the entire team involved with the improvement process, defined key ownership of improvement work and progress made till date. This was done via emails and reviewed in team meetings.
- To evaluate the results from the year prior to and after implementation of these tools:
- Mean HbA1c results for NPDA 2017/18 (n=218) and 18/19 (n=224) were compared using Two-tail Z-test.
- Health check completion rate were compared for the two years. The health check completion rate was obtained dividing the total number of key processes for CYPD over 12 years having full year of care in our PDU (n=124 in 2017/18, n=101 in 18/19), by the total 'expected' (7 X n) health checks.

Results

- Mean HbA1C in 18/19 showed a statistically significant decrease with p-value of 0.003.
- Median HbA1c levels in 2018/19 (63.5 mmol/mol) reduced compared to 17/18 (67.2 mmol/mol).
- The health check completion rate improved from 78% to 88.3%.
- CYPD getting 4 HbA1c tests per year improved from 62.6% to 100%.
- CYPD getting level 3 carbohydrate training within 14 days of diagnoses improved from 28.6% to 78.6%.
- CYPD getting sick day rule advise during annual review improved from 74.8% to 96.2%.
- CYPD getting additional dietetic 1:1 appointment improved from 85.3% to 94%.
- Ketone meter training improved 76.2% to 95.7%.

Conclusions Kaizen 'lean' interventions improved HbA1c and health check completion for our PDU. This was delivered without any additional financial impact to the service provider.