Case Study: Improving thalassaemia care

Addressing a recommendation from the Infected Blood Inquiry: Health Needs Assessment of people with thalassaemia

In 2024 the public health team SPH based in Arden and GEM was commissioned by NHS England to address one of the recommendations from the Infected blood Inquiry presented to Parliament in the same year.

The Infected Blood Inquiry, reported that from 1970 onwards failings in treatment using infected blood and blood products resulted in over 30,000 people being infected with HIV and one or more types of hepatitis, with around 3,000 people dying of those infections.

People with thalassaemia, a type of inherited genetic haemoglobin blood disorder, were subject to receiving infected blood during their standard treatment of regular frequent blood transfusions and suffered consequent harm from contracting infections. The Infected Blood Inquiry resulted in 12 overarching recommendations, many of which are relevant to people living thalassaemia. One recommendation specifically focused on people with thalassaemia stating that:

"*particular consideration be given, together with the UK Thalassaemia Society….., to how the needs of patients with thalassaemia ….. can best holistically be addressed.*"

NHS England, commissioned AGEM to carry out a qualitative and quantitative needs assessment of thalassaemia in England to address this recommendation.

The aim of this work was to:

- identify the health needs of people with thalassaemia across England,
- report health inequalities experienced by people living with thalassaemia,
- report variation in access and outcomes across England,
- identify gaps in service and opportunities to improve the health of people who live with thalassaemia,
- inform future policy and service development

We achieved these aims by synthesizing qualitative information from interviews and surveys with service users, patient representative organisations and professionals who provide thalasseamia care in addition to analysis of national data about treatment in different centres around the country. In addition, we carried out a document review of current policies, service specifications and peer review visit reports.

Context

Thalassaemia varies in severity from no symptoms at all to severe anaemia resulting in death if the individual does not have a regular blood transfusions that are closely managed and monitored over the life course. Iron overload resulting from regular transfusions is the main cause of a wide range of comorbidities including cardiovascular disease; liver disease; growth abnormalities; endocrine complications; bone disease; infections; enlarged spleen; infertility; and dental problems.

Managing the health care demands of living with thalassaemia, often results in service users having difficulties attending school, continuing with their studies and remaining in employment. This increases the likelihood of them becoming economically inactive. Professionals report that there are increasing numbers of people who require translation services including refugees and asylum seekers who arrive in this country in poor physical and psychological health requiring significant social support.

An additional intended benefit of the programme was to reduce carbon emissions, to help the Council meet its targets towards addressing climate change.

Outcomes

Both the qualitative and quantitative information identified some common key areas where services were not meeting the needs of people with thalassaemia. Inequities (avoidable or unfair differences) in the quality of thalassaemia service delivery across the country, were potentially leading to differences in outcomes for patients.

An action plan was developed framed around one high level action concerning national leadership, governance and accountability together with ten key themes that emerged concerning:

Theme 1: Improving workforce capacity and capability

Theme 2: Developing a system that worked better for patients where it was needed

Theme 3: Strategies to improve monitoring and management of the condition to reduce morbidity throughout the life course

Theme 4: Reducing variations in general access to services and clinical practice

Theme 5: Improving access to information, education, training and communication for professionals and service users

Theme 6: Improving data quality about treatment of thalassaemia patients and introduce digital solutions

Theme 7: Improving patient experience of thalassaemia treatment across the life course

Theme 8: Developing primary prevention strategies focussed on screening and awareness raising

Theme 9: Continuing and improving monitoring the quality of services delivered

Theme 10: Developing red cell research and innovation programme

Next steps

The key actions have been developed into a working document for NHSE with identified next steps that require implementation to improve thalassaemia care.

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