

Patient Experience and Engagement Strategy

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Document control

A patient experience and engagement strategy is a document, which changes and develops as the work of the NMCN progresses. It is recommended that a system of document control be used to keep track of previous versions.

Key personnel

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Version history

Version	Date of revision	Summary of changes	Changes marked
V0.1	March 2020	Initial draft	
V1	March 2020	Approved by PEG and Steering Group	

Distribution

Name	Organisation
CCS Patient Engagement Group	Various
CCS Steering Group	Various

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1 Background

Cleft Care Scotland (CCS) is a national managed clinical network (NMCN) which aims to improve services for people born with a cleft lip and/or palate throughout their life.

Cleft Care Scotland provides a framework to facilitate delivery of standardised quality patient care throughout Scotland. The network aims to ensure that patients are managed according to evidence based procedures and protocols and audits practice and outcomes of every centre against agreed standards, hence providing a basis for improving the quality of care.

Patient and carer engagement in the work of Cleft Care Scotland is essential to ensure the network is fully aware of the needs of people born with a cleft lip and/or palate and their carers, to support improved outcomes and experiences for people attending cleft care services in Scotland. This engagement will also form a strong part of the governance structure of the Network, helping to perform an assurance role. This strategy ensures that the process for engagement is open, considered, meaningful and transparent.

2 Scope

The Networks Patient Experience and Engagement Strategy describes how Cleft Care Scotland (CCS) will use the experiences of people born with a cleft lip and/or palate and their carers, and understand what matters to them to inform the activities of the network. This is central to the networks vision:

“Every patient with a cleft lip, cleft palate or cleft lip and palate is offered specialist cleft care from diagnosis to adulthood. We work with the family to offer the right care in the right place at the right time to produce the best possible outcome for the patient.”

The Network’s Patient Experience and Engagement Strategy has been developed by the Patient Engagement Group which includes patient and carer representatives and voluntary sector organisations with an interest in cleft care. The strategy will be regularly evaluated to ensure its effectiveness and approaches will be adjusted accordingly.

Strategic oversight of the strategy will sit with the CCS Steering Group. Operationally, the delivery of the strategy will be managed by the network Programme Support Officer and Programme Manager.

This strategy should be read alongside the networks Communication Strategy which describes how Cleft Care Scotland (CCS) ensures that all its stakeholders are kept informed and are able to influence the work of the network.

3 Patient Experience and Engagement Strategy

Cleft Care Scotland will engage with people born with a cleft lip and/or palate and their carers in a variety of ways:

- The CCS Patient Engagement Group will meet regularly and develop an action plan to support delivery of the networks Patient Experience and Engagement Strategy.
- Members of the Patient Engagement Group will be invited to participate in the CCS Steering Group to ensure the views of patients and carers are shared with and are able to influence to work of the wider network.
- An annual patient/carer event will take place, the format and content of which will be guided by the Patient Engagement Group in response to feedback from patients and carers. In addition to providing a forum for networking and sharing relevant information this event will also provide the opportunity for patients and carers to identify their priorities in cleft care.
- Patient experience surveys will take place annually to understand what is important to people attending cleft care services to find out what works well and how we can tailor services to better meet the needs of people born with a cleft lip and/or palate and their carers.
- 'You Said, We Did' documents will be developed following Network engagement activities to highlight what has happened in response to patient and carer feedback.
- The network will work in partnership with third sector organisations to support engagement with people born with a cleft lip and/or palate and their carers eg hosting joint events, using their communication channels to promote network activities etc.
- Patient and carer involvement will inform the development and review of patient resources (e.g. patient information leaflets, posters etc) to ensure these meet the needs of people attending cleft care services.
- The CCS website (<http://www.cleftcare.scot.nhs.uk>) will be reviewed in conjunction with patient and carers to ensure this is meeting their needs. The website will direct people with a cleft lip and/or palate and their carers to sources of information and support. It will also advise how to get people can get involved in the work of the network.
- The CCS newsletter (distributed by email and via the CCS website) will share information on the work of the network and highlight opportunities to get involved.