North West London’s approach to community and citizen engagement
Background to the Whole Systems Integrated Care Programme

In 2011, spurred on by an initial commitment to improve healthcare for older people and those with diabetes, a stakeholder partnership made up of various care providers from North West London (NWL), including NHS England, local authorities and voluntary organisations came together to find practical solutions to integrating health and social care. From this a pilot, called the Integrated Care Programme (ICP) was born, and ran until June 2014.

Building on the success of the pilot, 30 North West London health and social care organisations co-designed a long term vision of integrated care and services, for a population of 2.1 million. The approach centred on putting patients at the heart of their coordinated, joined up care. The new Whole Systems Integrated Care Programme (WSIC) programme launched in September 2013, and a year later, this underpinned NWL’s successful proposal to become one of the Department of Health’s “Pioneers” of integrated care.

NWL has developed:

- ICP pioneered a platform for equality across health and social care in NW London.
- Transformational new language from clinician centred care to patient centred care – moving towards an integrated system where a holistic view is taken of the patient needs by all stakeholders.
- Excellent long lasting working relationships built up over time through positive experiences.
- Lay group provided exemplar of how patient participation and co-design could work, inspiring co-production in the WSIC programme.
- Established multi-disciplinary groups across NWL bringing together primary, acute, mental health, community and social care.
- Risk-based pro-active primary care level care planning as a standard practice has been key component of the ICP.
The Lay Partners Advisory Group (LPAG) and the Lay Partners Advisory Group Forum (LPAGF)

From the outset, partners from NWL were keen to place patients and local community engagement at the heart of the WSIC’s development – particularly involving patients and carers to ensure service integration met their needs.

In order to support this, patients, carers and service users were invited to be part of a Lay Partners Advisory Group (LPAG). This group aimed to be representative of local communities to capture a wide range of views on local care provision and co-produce the NWL framework for integrating care.

From the LPAG the Lay Partners Forum was established in order to reach a diverse range of patients and service users from North West London.

A range of local and national organisations were also invited to participate in the group to represent the views of patients. One of the biggest challenges was to engage directly with patients. To overcome this, Age UK, national Diabetes groups, and others, were approached to identify patients who had previously actively engaged in similar focus groups and invite them to participate.

It was important to ensure that the LPAG members felt confident to participate fully in board-level discussions and to be able to challenge processes, ideas and new ways of working in order to ensure the views of patients served a role in determining and influencing change. To ensure the LPAG was able to ‘hit the ground running’ sessions were provided to coach, build capacity and skills in order to support them in engaging with the public sector. Over time the group has grown in confidence and developed a greater awareness of how integrated services should and could work. They now feel confident to raising concerns in all aspects of integration (in care) and are fully aware and understand the services that are being altered, changed and improved.

How the LPAG is different from other groups

North West London Collaboration of CCGs is proud that their approach is truly co-designed and recognises this as strength in the delivery of integrated services.

The LPAG is considered an equal partner to the ICP stakeholders. They feel their views are listened to and opinions not just noted, but are part of the decision-making processes. Members of the LPAG identify themselves as a ‘catalyst for change at the local level’.

The views and ideas of the LPAG have informed the development of the co-production principles of the WSIC programme, and they have worked hard to ensure that these principles have been embodied in all work to date.
How Lay Partners have been involved in the WSIC programme development to date:

The NWL WSIC Principles for Co-production:

1. Co-production for the Whole Systems programme starts with co-design, through which we can then embed co-delivery. This is the core of our programme and is embedded throughout the whole process.

2. We are dealing with new relationships for which we need a new language of inclusion: we will avoid “consultation” and aim at all times to have “conversations” for a genuine partnership.

3. We are people driven: we will actively reach out to those individuals whose voice is rarely heard.

4. We are all responsible for driving progress and educating each other along the way.

5. We recognise the political and social context in which the programme sits.

The NWL WSIC Principles for Co-production:
How the LPAG influences the integration of health and social care

The LPAG has played a significant role in the development of North West London’s WSIC programme and it has been commented that: “Part of the real value in what we have attempted to do, has been seizing the opportunity for everyone to grow and learn together”.

Through enabling the voice and opinions of local patients and carers to be heard, the programme has developed at pace, with a focus on delivering services that reach the right people to provide the right care in the right way.

This has been enabled by having those with direct experience of the system provide real examples of what is and isn’t working and suggest improvements that could be made.

WSIC LPAG has played an active role in overseeing the programme from a lay perspective by having membership of and involvement in:

- Working groups
- WSIC Governance Bodies
- Early Adopter Steering Groups at a local level
- Other transformation work, including engagement in workforce development, seven day services and information sharing

This involvement has, amongst other things, enhanced approaches for sharing information and providing accessible, jargon free communications.

The group has also informed the development of National Policy on Information Sharing in the NHS after being asked to comment on an NHS England ‘Fair Processing’ leaflet. Their feedback facilitated an in-depth discussion on ‘how do you tell a patient how the NHS works in a way that can be universally understood?’ and members of the LPAG challenged the language used in the draft version. This was then fed into the policy’s development.
How the LPAG supports information sharing

Information sharing is at the forefront of conversations by members of the LPAG as it supports the development of a shared vision for improved and joined up care. They recognise people still have major concerns about how personal information is shared and this is something the group hopes to address by ‘myth-busting’.

The LPAG is also supporting national programme development, so far they have commented on the development of NHS England’s Fair Processing Notice Workshop and the development of their patient communication material.

Benefits of establishing the LPAG

- Guarantees there is a patient or carer voice to contribute to conversations that directly affect and impact them.
- Has the strength to challenge controversial topics that have local and national implications and impacts.
- Wide representation of local communities and a broad range of viewpoints from those with the patient’s interest at heart.
- Supporting the cultural change which is needed to ensure patients are at the centre of their care in the integration of their care services.
- Local people “pushing the boundaries and pushing out bureaucracy” who are enabled to be ‘guardians of the vision’.
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