

Our WMAHSN manifesto for a Person Centred Care (PCC) Service

Context

Person Centred Care (PCC) is one of the key components, and central to, the WMAHSN's long-term vision. It is a key ingredient in ensuring a healthier region and must remain a central tenet to support the future affordability of NHS care.

This document presents the PCC service for person centred care. This applies to the implementation of evidence based care pathways, innovation and evaluation of health and social care services. This should ensure that all clinical priority programmes include most/all elements of PCC as relevant to the type of innovation. This is key since PCC, alongside other critical WMAHSN enabling themes, is a vital component of these programmes.

The PCC service cuts across all other WMAHSN themes, priorities and programmes – see Box. This positions PCC as part of a holistic AHSN innovation service, rather than a standalone programme of projects; with similar principles to those embedded in the NHS Constitution.

Box: WMAHSN clinical priorities, programmes, themes and services with which the PCC service supports, connects or is integrated

Clinical Priorities (CPs) and Programmes (Ps):

- CP Long term conditions
- P Technology enabled care
- P Back pain (STarT Back) and musculoskeletal pain
- CP Medicines safety
- P Medicines optimisation and adherence
- CP Mental health
- P Mental health crisis care
- P Medically unexplained symptoms
- CP Wellness and disease prevention
- P EIT Health KIC (healthy living and active ageing)
- CP Genomics medicine
- P Genomics ambassadors

Additional Cross-cutting Themes/Services:

- Digital health and big data service
- Innovation and adoption service
- Clinical trials and evidence theme
- Education and workforce of the future theme
- Wealth creation theme
- Patient safety theme

In essence we believe that person centred care is simply:

- Right care for the person's (or carer's) needs and preferences, delivered with dignity, compassion, sensitivity and respect, at the right time and place, with due regard to the person's age and any cognitive impairment

In addition, it is:

- Holistic care that includes physical, mental, emotional, spiritual, social aspects and person's own perspective and experiences – as appropriate
- Shared care: informed, value based, preference sensitive, agreed between person (and carer/family if appropriate) and care professional
- Safe: with informed decision making balancing potential benefits and risks where there are options for different routes and modes of delivery of care
- Designed and evaluated with public, community, patient input and feedback
- Proactive and inclusive of health promotion as well as primary, secondary and tertiary prevention
- Integral to a quality improvement culture in health and social care.

Summary of key thinking in relevant elements of Person Centred Care

1. Promoting care professionals' skills in person centred care

(i) Behavioural change

NICE recommends a solution-focused approach by care professionals that includes:

- Self monitoring by patient/service user of behaviour and progress (with agreed shared care management plan/goals)
- Goal setting (mutually agreed by care professional and person (and carer))
- Encouraging social support
- Problem solving (with patient/service user encouraged to report issues)
- Assertiveness – encouraging patients and carers to be assertive
- Cognitive restructuring by patient or carer (modifying thoughts)
- Reinforcement of changes (in behaviour/treatment/interventions by patient/carer)
- Relapse prevention/ individualised strategies.¹

(ii) Self management, self care

A care professional should consider shared management plans between person and care professional as a norm for a patient with a long term condition; or person whose lifestyle habit may adversely affect their health. They (one or all members of the care team) should be able to help a person (and carer) to understand their condition(s), suggest options for interventions which support the person to choose and maintain the right treatment for them and self-manage their condition(s) on an ongoing basis, taking into account their ability, cognition, skills and motivation. A care professional should be able to supply and engage a person with an appropriate decision aid (matching their values, preferences, knowledge and skills). So care professionals need to sign up to a culture of shared decision making and gain skills needed to communicate evidence and its limitations in ways that people understand using their preferred modes of delivery of decision aids (paper based, online, individualized, generic etc). The shared management plan should be accessible to all involved in delivery of care in line with patient informed consent.

Appropriate tools and information for patients and healthcare professionals, and workforce development/training will be developed as part of the implementation of the PCC service.

2. Generating, collating and acting on patient feedback

There is a UK-wide push to continuously invite individual patients' feedback – comments, complaints, suggestions – whether directly from a person/their carer or from a public organisation such as PALS. There is increasing attention given to national patient survey data with eg incorporation into national 'GP High Level Indicators' and local quality incentive schemes (e.g. Stoke-on-Trent CCG's Quality

Improvement Framework'). All NHS Trusts/CCGs/practices and LAs should be actively gathering feedback (eg with help from CSUs or public health teams) and share it with local patient/service user groups in an open and transparent manner. Care professionals should try to understand patients'/service users' perceptions in order to minimise barriers and provide person centred care.

All regional programmes supported by the PCC service will have active public involvement in the development, implementation and evaluation.

3. Engaging the public and service users of health and social care in service development and service redesign

All CCGs and provider Trusts/practices should be actively engaging patients/service users and the public in shaping the services they use and that the NHS/social care provide (or should provide); overcoming system 'inertia' and NHS/LA 'know best' attitudes. This might be as a 'partnership' model and co-production of service design or applications.

Commissioning for Better Outcomes describes what matters most to people from CCG and local government perspectives:²

- 'The person at the centre, rather than fitting them into services.
- People who use services and carers treated as individuals.
- Empowering choice and control for people who use services, and carers.
- Setting goals for care and support with people who use services and carers.
- Having up-to-date, accessible information about services.
- Emphasising the importance of the relationship between people who use services, and providers and staff.
- Listening to people who use services and acting upon what they say.
- A positive approach, which highlights what people who use services can do and might be able to do with appropriate support, not what they cannot do.'

Partnership and planning between the general public and communities and the NHS are an essential element of the NHS *Forward View*.³ '...empowering patients and engaging communities are all essential components of creating a sustainable NHS.....give patients choice over where and how they receive care in line with their legal rights set out in the NHS Constitution and the statutory duties of NHS England and CCGs to promote choice....to make significant further strides to honour patients' entitlements to choose.....focus on actions to improve the way that the NHS engages with communities and citizens, including with local HealthWatch, involving them in decisions about the future of health and care services.'³ Local needs assessments should be inclusive and based on organisational and sectoral priorities (physical health, mental health, social care, housing, benefits etc) to create a more integrated 'whole person' approach.

All regional programmes supported by the PCC service will have included active public and patient/service user involvement in their development and in subsequent evaluation following their implementation.

4. Sharing of a person's medical records

Online access in general practice to a person's medical records, booking of appointments and ordering repeat prescriptions is usually available to patients. Soon individual patients should be able to request that access to their general practice records is extended to other clinicians. Access to a person's medical records will

need to be underpinned by appropriate clinical governance for safe care management, and information governance for conserving patient confidentiality and safe data sharing (mode of access needs to be flexible). Recent legislation has endorsed the use of a person's NHS number so that all organisations in health and social care identify the individual person in the same way with a view to sharing personal data in valid, reliable and safe ways.

Midlands and Lancashire CSU is creating pilots of the use of GraphNet to share data about an identifiable patient with clinicians from different health settings (eg primary and secondary care). It is critical to establish medicines-related communication systems when patients move from one care setting to another to minimise errors, delays or omissions of medicines.

All regional programmes supported by the PCC service and the digital health and big data service should endeavour to include evaluation across a person's care pathway ensuring compliance with all aspects of information governance in the process.

5. Empowering service users of health and social care about their own care

Empowered individuals with good access to their health and care information should have opportunities to use this resource to better manage their own health. They should be enabled (supported and educated) to gain the knowledge, skills and confidence they need to effectively manage their symptoms and condition(s) themselves so that they are able to make informed decisions and adhere to their medicines and treatment plans to achieve the best possible outcomes.⁴ The culture of the health or social care frontline should be one that welcomes and encourages a person's commitment to change and improve their health and wellbeing (e.g. the person may wish to use an appropriate app to link their own generated health information to their medical records or care plan).

A self-management plan or other care plan should be in an accessible format and include:

- Start and review dates
- Describe condition(s)/lifestyle habit(s) being managed
- Current treatments including: frequency of use, flexibility in doses of medicines, any restrictions
- Arrangements for follow up with a responsible care professional if condition deteriorates, side effects from medicines etc

'Everyone with a diagnosed long term condition should be guaranteed a healthcare plan covering their physical health, mental health and social care needs, into which they (and their carer/family as appropriate) have substantial input and which they develop in partnership - and jointly agree - with their healthcare professional or care coordinator. Healthcare plans should include peer-to-peer support and assistive technology as a matter of course.'⁵ A person's care plan should be shared by their responsible health or social care practitioner.

These key elements which will empower individuals will be incorporated into the PCC service supporting better access to individualised information, new technology, clinical decision tools and care pathways that support personalised treatment.

6. Patient decision aids and clinical decision support tools

NICE⁴ emphasises that putting a person at the centre of decisions about their care can enable them to use the medicines that they are prescribed safely and effectively and get the best possible outcomes and mode of care that the person values.

Shared decision-making is central to the delivery of evidence based health or social care. Everyone should be offered the opportunity to be involved in making decisions about delivery and scope of their care. Where there is more than one reasonable option, each with potential benefits and harms, the use of a high quality patient decision aid can facilitate patient engagement and empower patient input into choice of selected option.

A patient decision aid should describe the options available in a way that the person is likely to understand; and help the patient make an informed, value based, preference sensitive decision with the care professional after weighing the specific risks and benefits of options.^{4,6} The care professional should feel confident about the content and appropriateness of the chosen decision aid – and the balanced way that risks and benefits are described. Information systems that provide decision support to users at the time they make decisions should enhance evidence based practice and thus the quality of care provided.⁷

Ensuring the quality and timeliness of decision aids is a challenge.⁸ The PCC service will work with regional programmes to identify and develop new approaches to applying patient decision aids and clinical decision support tools that have a strong evidence base to demonstrate that they provide a person with the right treatment in the right place at the right time.

7. Patient safety

Patient safety from the person's perspective includes:

- Holistic care plan
- Medicines reconciliation - for comorbidities and when a long term condition is diagnosed/treatment changed etc; or health or social care provision of person's care changes setting or extends across multi-settings
- Learning from past patient-safety incidents to minimise the likelihood of similar incidents occurring in future.

The PCC service working with the patient safety theme will incorporate monitoring of safety as part of the ongoing evaluation of regional programmes

8. Patient centred evaluation

Patient-reported outcome measures (PROMs) are commonly used in health economic evaluation to evaluate outcomes of health interventions, in economic evaluations of medical technologies and to compare the performance of health service providers.⁹ PROMs might be condition specific, focused on a specific aspect of health. Generic PROMs measure health related quality of life generally – enabling comparisons of health across conditions and health services.⁹ 'Evaluation of a person centred approach should focus on the elements of care and support and treatment that matter most to the patient, family and carers; you might gather qualitative and quantitative data to measure their experience of care based on principles of person centred care¹⁰:

- dignity, compassion and respect;
- co-ordination of care, support or treatment;

- personalised care, support or treatment;
- support for person to recognize and develop their own strengths and abilities to live an independent and fulfilling life.¹¹

The PCC theme will roll out specific guidance and toolkits for PROMS to ensure and demonstrate the value of linking person centred evaluation to service evaluation.

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