



# **A New Model to Encourage Person-centred Approaches to Long-term Condition Management In Primary Care**

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## Abstract

Why do we need new, more person-centered models for long-term condition (LTC) management in primary care? We want primary care services to support people living with LTCs to achieve the Institute Healthcare Innovation's (IHI) quadruple aim of better health outcomes and experiences, lower costs and higher staff satisfaction.

Current evidence suggests that the most effective way to achieve the quadruple aim is when the wider determinants of health (such as loneliness, inactivity, or poor diet) are addressed alongside what the current health care system delivers. Health care systems should seek to integrate approaches known to effectively improve these wider determinants of health. This paradigm shift is not easy to achieve in the context of pressures in the current health care system. The author proposes a simple model that is feasible to implement in a primary care setting, with minimal additional resources. A model that highlights the need for equal emphasis to be applied to both assessing a person's capability to look after themselves and the traditional markers of disease. While considering the most efficient and effective population level approach to do this. We demonstrate a systematic, efficient approach to resource distribution, tailored to individual need that helps patients become more activated and self-caring. It offers a framework upon which primary care systems can develop new service and approaches. A first step on a journey towards person centered systems.

## Introduction

The IHI has proposed that the main aim of health care should be the triple aim of improving health outcomes and experience and reducing per capita costs<sup>1</sup>. A fourth is often quoted in the 'quadruple aim', where we consider the 'joy of work' for staff as well<sup>2</sup>.

In achieving the quadruple aim the most significant challenge facing western health systems is the management (and prevention) of LTCs. It has been reported that they account for 50% of all GP appointments and 70% of all NHS resources.

Whilst planned, proactive management of long-term conditions might seem like it should be the priority in the NHS if we are to achieve the quadruple aim, it is often overshadowed by more immediate demands. Resource tends to be drawn to the 'front door' of people demanding appointments or admission to hospital for acute symptoms and crisis. In the context of the workforce crisis in primary care, high quality long-term condition management can be a low priority in a generalist setting.

When studies have looked at what produces good health outcomes in populations, perhaps surprising to many working in health care services, it is not the health care systems that contribute most to good health. The major contribution is from the person (and their carers), and the social context in which they exist, often termed the 'wider determinants of health'.

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<sup>1</sup> <http://www.ihl.org/Topics/TripleAim/Pages/default.aspx>

<sup>2</sup> <http://www.ihl.org/communities/blogs/the-triple-aim-or-the-quadruple-aim-four-points-to-help-set-your-strategy>

In the major studies looking at what contributes to good health; lifestyle choices, behaviours and social conditions outweighs health systems by a factor of 2-5 times, depending on the study<sup>3, 4, 5, 6</sup>.

This theme has been picked up in recent work led by Nesta and The Health Foundation. In their 2-year programme, *Realising The Value*<sup>7</sup> (RtV), they explore significance of person centred and community centred care, and how to deliver it. They propose a new value set with a much stronger focus on valuing independence, empowerment, and social connections. They present a strong economic case for these approaches.

In terms of how to do it, Person Centred Care (PCC), is a very deliberate approach. It draws on both evidence and experience bases. It focuses on coordinated, personalised, and enabling care<sup>8</sup>. Central to this approach is often a new type of collaborative conversation that gives equal priority to what matters most to the person, and the concerns of the health care professional. RtV highlights how effective activities such as peer support, education for self-management, health coaching, group activities, and asset based approaches can be. NHS England recognize that most often this involves mobilization and integration of assets in the community, often the voluntary or charitable sectors. Delivery of person centred approaches in the community is often talked of as 'social prescribing'. Some feel that using the word 'prescribing' still over medicalizes this approach. I would suggest it represents a needed compromise as we traverse the gap between current medical systems and the new paradigm that embraces PCC as core to standard practice.

Sheffield Clinical Commissioning Group has been supporting implementation of PCC in primary care settings<sup>9</sup>. The report of learning from the first 3 years highlights some of the challenges. In particular how complex paradigm shifts can be broken down into manageable steps of change, without losing the perspective of the end vision. The danger is that achieving the small steps is seen as 'job done'.

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<sup>3</sup> McGinnis, J.M., Williams-Russo, P. and Knickman, J.R. (2002) The case for more active policy attention to health promotion. *Health Affairs* 21 (2) pp.78-93.

<sup>4</sup> Canadian Institute of Advanced Research, Health Canada, Population and Public Health Branch. AB/NWT 2002, quoted in Kuznetsova, D. (2012) *Healthy places: Councils leading on public health*. London: New Local Government Network. Available from [New Local Government Network website](#)

<sup>5</sup> Bunker, J.P., Frazier, H.S. and Mosteller, F. (1995) The role of medical care in determining health: Creating an inventory of benefits. In, *Society and Health* ed Amick III et al. New York: Oxford University Press. Pp 305-341

<sup>6</sup> Dahlgren G, Whitehead M (1993). Tackling inequalities in health: what can we learn from what has been tried? Working paper prepared for the King's Fund International Seminar on Tackling Inequalities in Health, September 1993, Ditchley Park, Oxfordshire. London, King's Fund, accessible in: Dahlgren G, Whitehead M. (2007) *European strategies for tackling social inequities in health: Levelling up Part 2*. Copenhagen: WHO Regional office for Europe: [http://www.euro.who.int/\\_data/assets/pdf\\_file/0018/103824/E89384.pdf](http://www.euro.who.int/_data/assets/pdf_file/0018/103824/E89384.pdf).

<sup>7</sup> <http://www.nesta.org.uk/project/realising-value>

<sup>8</sup> <http://www.health.org.uk/sites/health/files/PersonCentredCareMadeSimple.pdf>

<sup>9</sup> <http://www.sheffieldccg.nhs.uk/Downloads/About%20US/Documents%20Policies%20and%20Publications/Person%20Centre%20Care%20in%20Sheffield%20%202016%202017.xps>

## Background theory and policy

Perhaps the first pioneer of new models for LTC management was Ed Wagner with his Chronic care model<sup>10</sup>. He described 6 areas to focus on (including self-management and community engagement), implemented as part of a robust quality improvement process. His team's experience of implementation across over 100 primary care organisations was challenging. It required whole system changes, often met with resistance from patients and staff<sup>11</sup>, or disincentivised by payment systems<sup>12</sup>

This approach was acknowledged as the guiding framework, in WHO's call for a global transition from a predominantly acute disease model, to a chronic disease model<sup>13</sup>. More recently this was adapted into a formally adopted framework for integrated people-centred health services in May 2016<sup>14</sup>

The Health Foundation built on this model in its Co-creating health programme<sup>15</sup>. This was a well evaluated 5-year programme. It recognised the need for a simultaneous 3-dimensional approach of support and training for patients and professionals, and organisational development of the system, in adopting a PCC approach. It also highlighted the professional barriers to change:

*"... real and perceived dilemmas about risk, patient safety and the professional's own risk management which may constrain their ability and willingness to adopt self-management support and other patient-centred practices"*

The programme stressed the need for successful supported self-management to be ongoing and not 'add-on'. As such I would suggest UK primary care is ideally placed as an enduring delivery vehicle for PCC.

This systematic approach was expressed as the 'House of Care' by the Year of Care Partnership<sup>16</sup>, who described the system with commissioning processes as 'foundations' and supporting processes and tools as the 'roof', held up by the 'pillars' of activated patients and skilled HCPs. These 4 components are essential if you want to build a home for person centred care. They specifically highlighted the benefits of this approach in diabetes care<sup>17</sup>. The intention was for a more person centred approach to replace the current annual review process, as currently contracted in the primary care Quality and Outcome Framework. The Year of Care (YOC) approach takes account of 'what matters' to the individual as well as 'the system' and offers a personalised menu of options that are either 'medical' or more 'psychosocial' focused, orientated around wider determinants of health.

The model was taken up by the Royal College of GPs, expressed as a 'care planning approach'<sup>18</sup>. The Year of Care team also highlight the important and unique role that Non-Traditional Providers (NTPs- such as voluntary organisations, community groups and social enterprises) deliver in a system that joins them into primary care services, to produce person centred care<sup>19</sup>.

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<sup>10</sup> Wagner EH. Chronic disease management: What will it take to improve care for chronic illness? *Effective Clinical Practice*. 1998;1(1):2-4.

<sup>11</sup> Wagner et al, Improving chronic illness care: Translating evidence into action. *Health Affairs*, 20, no.6 (2001), 64-78

<sup>12</sup> Boheimer part 2 paper

<sup>13</sup> Innovative care for chronic conditions. World Health Organisation 2002

<sup>14</sup> [http://apps.who.int/gb/ebwha/pdf\\_files/WHA69/A69\\_39-en.pdf?ua=1&ua=1](http://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_39-en.pdf?ua=1&ua=1)

<sup>15</sup> Evidence: Co-creating Health: Evaluation of first phase 2012 The Health Foundation

<sup>16</sup> <https://yearofcare.co.uk/>

<sup>17</sup> Graffy, J., Eaton, S., Sturt, J., & Chadwick, P. (2009). Personalized care planning for diabetes: Policy lessons from systematic reviews of consultation and self-management interventions. *Primary Health Care Research & Development*, 10(3), 210-222. doi:10.1017/S1463423609001157

<sup>18</sup> Care Planning- Improving the Lives of People with Long Term Conditions, 2011 RCGP

<sup>19</sup> Thanks for the Pertunias, 2011 Year of Care Partnership

The NHS Five Year Forward View set out a central ambition for the NHS to become better at helping people to manage their own health: ‘staying healthy, making informed choices of treatment, managing conditions and avoiding complications’. They say “Evidence tells us that supporting patients to be actively involved in their own care, treatment and support can improve outcomes and experience for patients, and potentially yield efficiency savings for the system through more personalised commissioning and supporting people to stay well and manage their own conditions better”.<sup>20</sup>

NHS England has proposed that patient activation sits at the heart of self-care support<sup>21</sup>. Patient activation describes people’s skills, knowledge and confidence to manage their own health care (self-manage, or self-care). It can be effectively measured using the Patient Activation Measure. Evidence from a range of countries suggests that higher PAM scores correspond to better health outcomes, better experiences of care, and more appropriate use of resources, as described in the King’s fund review paper<sup>22</sup>. PAM has been validated for use as a tailoring tool, and this paper describes previous examples of segmenting populations according to both disease burden and activation on page 28. Research suggests that the most effective way to increase people’s activation is to use a coaching approach tailored to their starting level of activation<sup>23, 24</sup>.

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<sup>20</sup> <https://www.england.nhs.uk/ourwork/patient-participation/>

<sup>21</sup> <https://www.england.nhs.uk/wp-content/uploads/2016/04/patient-activation-narrative.pdf>

<sup>22</sup> <https://www.kingsfund.org.uk/publications/supporting-people-manage-their-health>

<sup>23</sup> <http://www.ajmc.com/journals/issue/2017/2017-vol23-n2/an-examination-of-the-relationship-between-care-management-with-coaching-for-activation-and-patient-outcomes?p=1>

<sup>24</sup> Improving the outcome of disease management by tailoring care to patient’s level of activation, Hibbard et al, American Journal of Managed Care, Volume 15, Issue 6, June 2009, Pages 353-360

# An Initial Model for Implementing Person-Centred Care for Long-Term Conditions

Despite the case for change being compelling, my experience working as a GP commissioner at organisation level and GP partner at the coal face, was that moving towards person centred care still felt like an overwhelming and difficult system change. Evidence suggests that ultimately we need to embrace sustained whole system change. But how to start? So, my proposition was to draw on the evidence, to create a pragmatic and simple model, that could support a realistic and acceptable option, for these first steps.

The proposed model 'The Quadrant model', is a starting point in thinking about manageable early steps of change, towards a systematic person centred approach to LTCs. It recognises the need for it to be simple enough to understand and implement but starts to drive ways of working that support the theory and policy aims described above. It should not generate extra work for an overwhelmed system, and ideally should identify where low value health activity can be reduced to increase capacity. It supports making best use of assets that tune into the wider determinants of health, be they from the person themselves, their support systems, or the communities they live in. It seeks to make best use of non-traditional providers of care, where they are most likely to have bigger impact than traditional providers.

A similar approach used by The Peace Health Patient Centered Medical Home was described by Hibbard and Gilbert in their Kings Fund paper. Their report suggested that 'by classifying patient populations by both disease burden and activation level, it is possible to achieve better outcomes than with a 'one-size-fits-all' approach, given the same amount of resources<sup>25</sup>. The quadrant model applies this approach to the resources and providers available in the NHS.

The Quadrant model uses 2 axis. The X axis is labelled 'medical complexity' determined by the accepted targets of well controlled LTCs. These are well documented in mainstream guidance such as NICE guidelines and QoF targets, but the division of high or low complexity should be considered for each patient in their context. The Y axis considers a new dimension related to patient capability to self-manage. The PAM is used as a valid and manageable determinant of this, being acceptable and simple for use in primary care<sup>26</sup>.

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<sup>25</sup> Blash L, Dower C, Chapman S (2011). *PeaceHealth's Team Fillingame uses Patient Activation Measure to customize the Medical Home*. Research brief. San Francisco, CA: Center for e Health Professions.

<sup>26</sup> <https://www.england.nhs.uk/wp-content/uploads/2015/11/pam-evaluation.pdf>

As well as assessing skills knowledge and confidence to self-manage there is evidence that PAM correlates well with other measures of 'person centredness'<sup>27</sup>, including patient experience<sup>28</sup>, mental and physical health outcomes<sup>29</sup>, and behaviour changes and quality of life<sup>30</sup>

Using a simple 'high' or 'low' dichotomy of these 2 axis produces 4 groups. This allows a segmentation or matching of different approaches to the 4 groups:

**Letter Group-** Low complexity (appropriately controlled disease markers) and high activation (PAM Level 3 or 4), would be determined as doing fine, and be treated with a light touch. In practice this involves writing them a letter to congratulate them on how they are doing, and encouraging them to do more of the same.

**Practice group-** High complexity (one or more markers of disease control not met) and high activation. The working assumption is that with higher activation people are more ready for a conversation with a stronger focus on medical management and medical focused goals and activities. Therefore, this group are invited into the practice for review with a doctor or nurse, who is given longer to have a coaching style consultation.

**Wider support group-** High complexity, low activation (PAM level 1 or 2). The working assumption here is that people in this group are more likely to struggle to interact well with a purely medical model. They are more likely to be overwhelmed with other life issues, with health care low on their list of competing priorities, or feeling under confident or under-skilled to take on self-management. They may well appreciate the more holistic approach that could be offered by a NTP, as an initial point of contact. They can give them more time, and consider a wider range of issues beyond just health. It would still be important that they are offered medical service input, but on the terms that best suit the patient. There would be a strong focus on collaboratively agreed 'small steps' (health or otherwise), with primary aim to build a patient's confidence.

**Prevention group-** Low complexity, low activation. People in this group satisfy traditional medical targets but the assumption is their low level of activation puts them at risk of future poor disease control and they may well benefit from support to build their activation. This might include considering their health literacy, and their wider circumstances and coping skills.

### **Systematic, but retaining patient choice**

The benefit of such a segmented approach is that it systematically directs people towards what is most likely to be the best value approach for them and the system. In practice, there is risk that patients either disagree with the outcome of this assessment process, or prefer a different option. To mitigate this, people in the 'letter' group are offered ways to access alternative options in their letter. People in the 'practice' group are still offered the services of non-traditional providers, like social prescribing, during their appointment.

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<sup>27</sup> Skolasky RL, Green AF, Scharfstein D, Boulton C, Reider L, Wegener ST. "Psychometric properties of the Patient Activation Measure among multi-morbid older adults." *Health Services Research*. Vol. 46 (2): 457-478. April 2011.

<sup>28</sup> Greene J, Hibbard JH, Overton V, Sacks R. "When Seeing The Same Physician, Highly Activated Patients Have Better Care Experiences Than Less Activated Patients." *Health Affairs*. 32:71299-1305. July 2013. <http://content.healthaffairs.org/content/32/7/1299.abstract?sid=027c7c13-43fe-4216-b848-fce10ce53979>

<sup>29</sup> Smith SG, Curtis LM, Wardle J, von Wagner C, Wolf M. "Skill Set or Mind Set? Associations between Health Literacy, Patient Activation and Health." *PLoS ONE*. September 2013. <http://www.plosone.org/article/info:doi/10.1371/journal.pone.0074373>

<sup>30</sup> Hibbard JH, Mahoney ER, Stock R, Tusler M. "Do Increases in Patient Activation Result in Improved Self-management Behaviors?" *Health Services Research*. 42(4). August 2007. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1955271/>

People in the 'wider support' or 'prevention' group are offered choice. Our experience is that this is best delivered by a one-to-one 'shared decision' conversation, usually by telephone, with an experienced 'health navigator'. This would be someone familiar with the range of NTPs that might best fit their needs, but also allowing them to decline this support and come to the practice for a review as in the practice group.

## **A Care planning Approach**

A key feature of this model is that all staff involved in delivery of all segments, inside or outside the practice should be trained and skilled in delivering a collaborative care planning approach (as described earlier in the RCGP model) and should understand the activation concept. This draws on a range of person-centred skills, well described by Health Education England<sup>31</sup>. We recognize that this sort of consultation benefits from more time. The advantage of this model is that it identifies people who either do not need to be seen this year, or who are best seen by other services, allowing primary care teams to allocate more time to the practice group, without the need for increased capacity.

Within a care planning approach is the ethos of building on people's assets. It has been highlighted by patient champions that those in the 'letter group' who are managing well, could be utilized as an asset to help others if they are willing.

The model also relies heavily on PAM outputs in the decision making, as such it is important that it is administered in a consistent and appropriate way to reduce potential biases, which could adversely affect the grouping of patients.

## **Approaches of non-traditional providers**

We worked with the providers delivering care options to the prevention and wider support segments. We recognised that they had strong experience in delivering 'strength-based' approaches and had well established networks of community connections. We didn't want to dictate too strongly what they would do, other than as stated above. We encouraged the NTPs to focus on helping people to gain insight into what mattered most to them, how health fitted into that (if at all), and what they most like to do to build their wellbeing. The NTPs often used their own resources or connections to enable people to take part in activities they wanted. This might be physical activity, learning new skills, or connecting with new people or groups. They were encouraged to direct people back to the practice team when they jointly (NTP and patient) felt medical input was appropriate for them.

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<sup>31</sup> Person-centred Approaches Core Skills Education and Training Framework, 2017 Health Education England

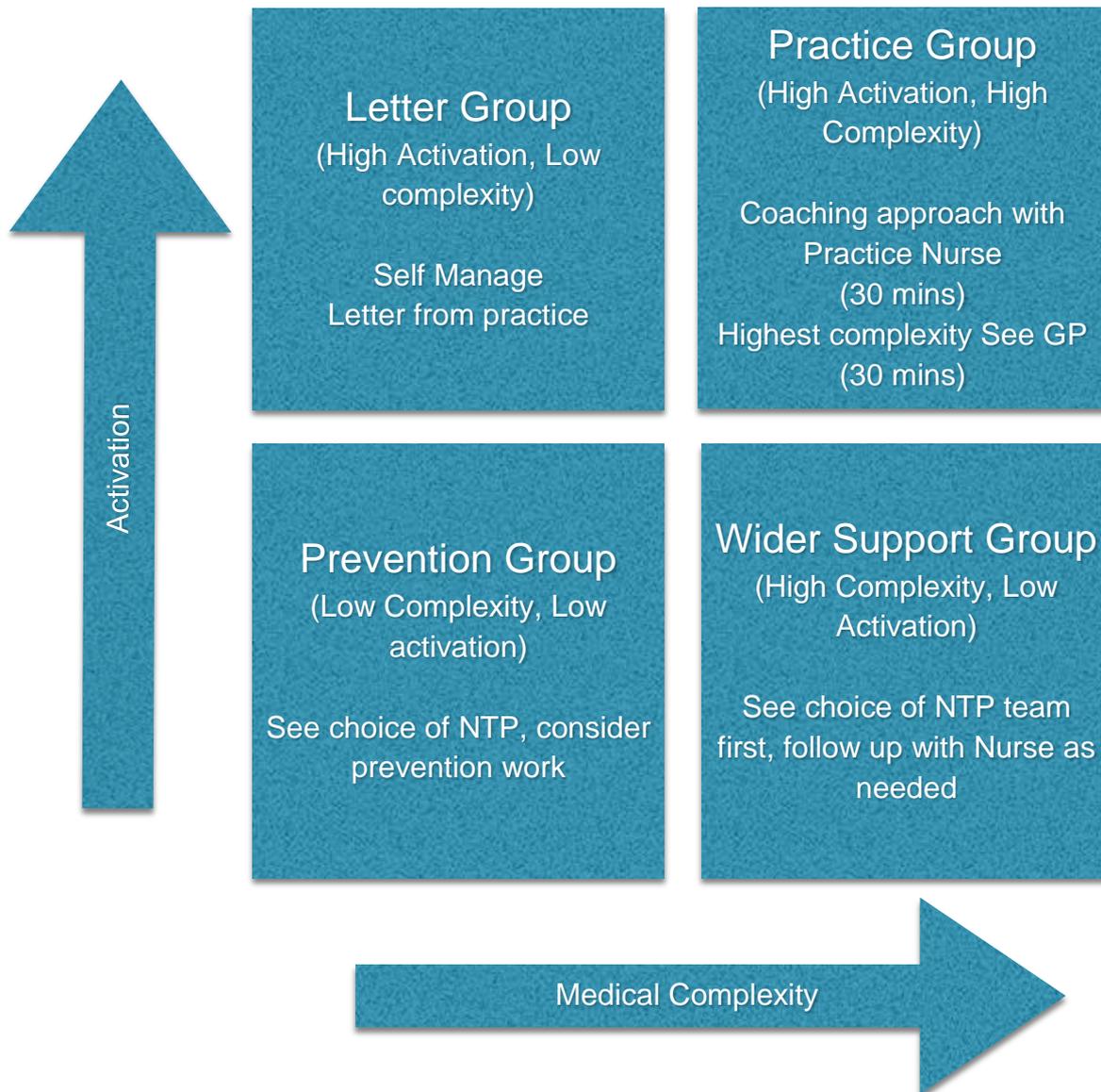


Figure 1. Quadrant model, adapted from presentation by Dr Ollie Hart at World Health Innovation Summit, Carlisle, March 2016

# Pilot of the Quadrant model for annual review for people with diabetes

This approach has been piloted in the Sloan Medical Centre in Sheffield, an urban GP practice covering 13,000 patients. The pilot cohort selected people living with diabetes, not being managed by the specialist diabetes teams. All patients were invited in their birthday month for an appointment to gather baseline data (BMI, BP, Foot check, Bloods, urine test, PAM). Patients were triaged into one of the 4 segments on the basis of these results. Medical complexity was assessed on a case by case basis considering appropriate targets for that person's diabetic care.

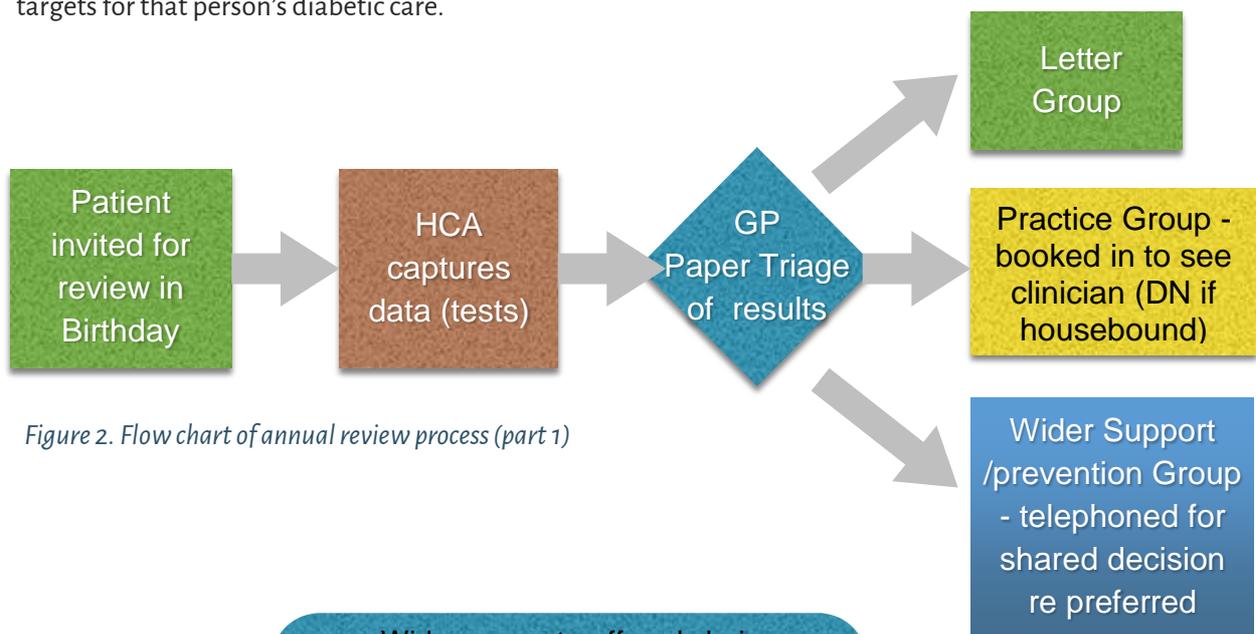
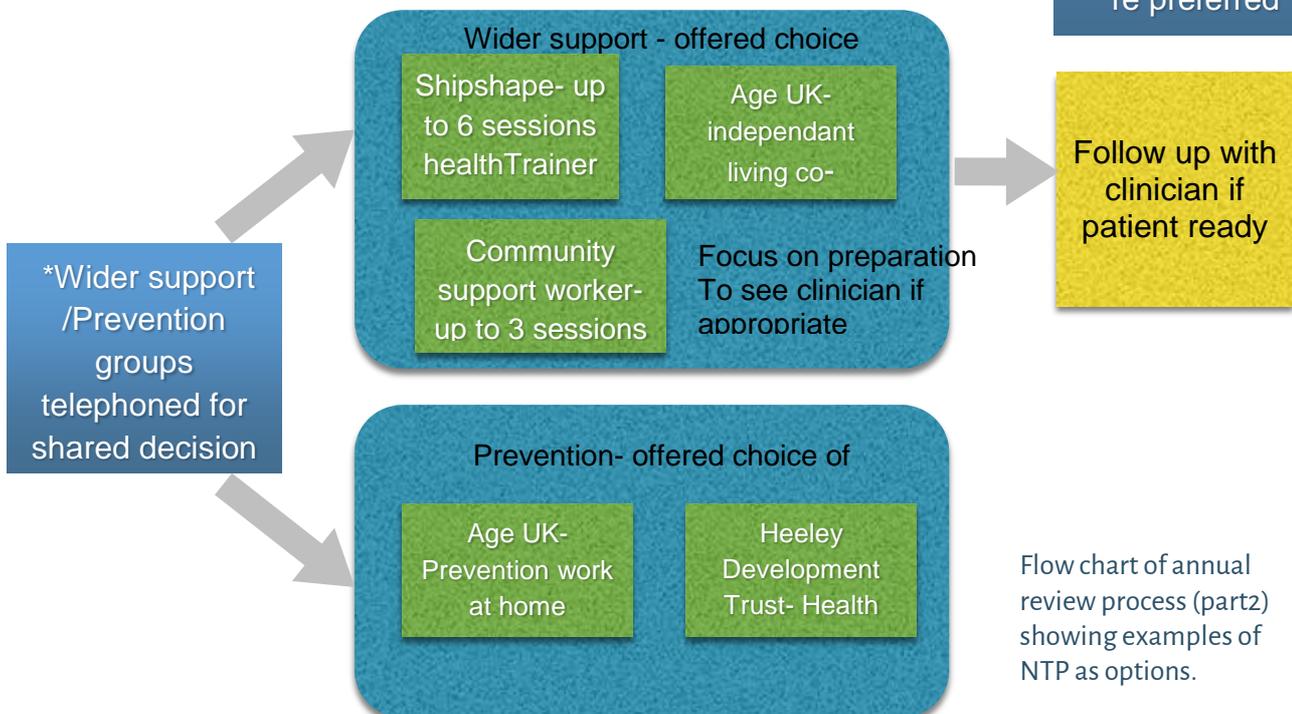


Figure 2. Flow chart of annual review process (part 1)



Flow chart of annual review process (part2) showing examples of NTP as options.

# Outcomes from pilot approach in diabetes (October 2016/17)

## Numbers

Total cohort = 655 people in Sloan Medical Centre with diagnosis of diabetes  
55 (8%) people refused/did not respond to x3 invitation for annual review  
40 (6%) managed by specialist teams  
118 (18%)- incomplete data set, mostly those in whom no PAM score was captured for a range of reasons.  
447 (68%) patients grouped via the Quadrant Model

Of the 447 people grouped, the portions of people in each group were distributed as:

Letter Group	=24%- sent letter reassuring all ok
Practice Group	=38%- invited to see the practice nurse/ or seen by GP
Wider Support Group	=20%- offered community support
Prevention Group	=18%- offered community support

Of those people in wider support/ prevention groups, offered 'NTP support' through a shared decision making process, 76% accepted, and 24% declined (and where mostly seen by the practice team if in wider support group, and left alone in prevention group).

Practice patient feedback was proactively sought via the patient participation group, through enquiry in face to face appointments, and at a diabetes patient group. This last group included 15 patients who had experienced the new quadrant model over the preceding 12 months.

The feedback was that the patient body felt this was an appropriate and acceptable model to pursue. Some people who fell into the letter group, identified the value of an appointment to help 'maintain their motivation'. However, they acknowledged that this could be seen as a lower priority in a system under strain.

## Medical outcomes

We were concerned to check that our process was not leading to a decline in the numbers of people hitting recommended medical guidelines, and causing harm. We did a snap shot of those patients recorded as meeting guideline targets at the start and end of the pilot. We used an established audit process set up by diabetes UK. There was a slight decline in those hitting a target hba1c of 53 (49% to 47%), but overall the number of people reaching guideline targets in all 3 BP, Lipids and HbA1c increased from 21% to 24%, with particular improvements in Blood pressure target attainment (49% up to 76%).

## Discussion

It is probably too early to understand the eventual outcomes that this Quadrant Model may lead to. The underlying premise of this process is to start to systematically measure and address person centred factors (like patient activation) as well as medical markers of disease control. The benefits of this approach are likely to take time to manifest. The evidence suggests focusing on developing person centred factors like activation leads to long term and sustainable improvements of health, that do not rely on medical input. It is often the case that purely medical management of LTCs like diabetes can lead to a passive role played by patients as they rely on doctor led prescribing to control their 'numbers' and take a less active role in addressing lifestyle behaviours.

We recognise that behaviour change is complicated. Too often all the blame for not changing behaviour gets levelled at the individual, when in fact environmental factors, societal norms, and automatic learned behaviours can have a far more significant impact than conscious decision making on the part of the individual. Policy makers have been criticised for not recognizing this to date<sup>32</sup>. I would suggest that the health system, and the terms on which a professional-patient relationship exists, should give much more parity to the capability the person has in generating good health for themselves. We should be fighting for policy to redress those wider influences on behaviour too, but not let waiting for these to change stop us from changing the things within our control in health services. There is clear evidence on how we can behave as professionals individually, or how we can organize our systems of care to have most positive effect on our patient's capabilities<sup>33</sup>. I would argue it is our duty as health care professionals to do so, and in doing send a powerful message for our patients, colleagues, and wider society.

The model relies on having good access to NTPs of care. We recognize that in certain circumstances, for some people these types of services offer support and interventions most likely to have the greatest effective on improving health at that time. Despite the evidence base supporting this, we realise there is a leap of faith in this approach, and often health care providers are worried about the risk of 'letting go'. There is also a concern that the funding for these NTPs is often short term and fragile, this has certainly been our experience in Sheffield. This can lead to high turnover of staff and services, necessitating new training and relationship building. If we are to develop systems that make best use of these services we must ensure they are adequately and sustainably resourced, and valued as being as important as medical interventions.

It is important however that this model doesn't lead to fragmentation of care, with people directed off to activities and support outside the practice without also addressing medical management where ever it will have good impact. It is important that NTPs remain close contact and communication with the practice so that medical advice and interventions can be included in the care plan that is made with people. When this is done well NTPs can help people to judge which interventions will best suit them, and prepare for and make best use of medical input when appropriate. This model requires a joined-up team approach with all stakeholders involved, with frequent sharing and refining of process and experiences.

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<sup>32</sup> Why is Changing Health-related Behaviour so Difficult? M.Kelly and M.Barker, Public Health Vol 136, pg109-116, July 2016.

<sup>33</sup> <https://www.nice.org.uk/guidance/ph6/resources/behaviour-change-general-approaches-pdf-55457515717>

## Next steps

This model has only been piloted in people living with diabetes, and only really considering the diabetes aspect of their medical care. This suggests that this approach is feasible, acceptable and at least in the short term does not lead to any harm to patient care.

The next step would be to roll out the approach considering the range of diseases that often co-exist in people with multi-morbidity. This would require some consensus as to what constitutes high or low complexity on the medical axis, ideally individualized to the patient.

We need to continue to monitor the effects of such models on a wide range of health and wellness outcomes, to check they are not leading to unintended consequences or enhancing health inequalities. We also need to assess how much cost savings are associated with the model and what efficiencies are actually realized.

We should consider how technological advancements can support the development of more sophisticated models, supporting better access to personalised information, and generating feedback and motivation on behaviour change. First steps might be ensuring patients can access their own medical records, next steps might be for people to own and develop their own records in partnership with their healthcare providers.

Personally, my aspiration would be that we steadily and critically develop such models at the pace our health systems, professionals and patients can tolerate. I hope we continue to make steps towards a systematized approach to person centred care. The ultimate best outcome would be more activated people and communities, living with better health, with less reliance on medical interventions. I believe this is the best way to achieve IHI's quadruple aim.