# The 2,000 days project

# Practical ideas for reforming health and care

October 2017



What if we transformed care for the first and final 1,000 days of everyone's life?

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# Introduction

A new approach to NHS reform.

s we approach the 70th anniversary of the founding of the NHS, and the mid-point of the Five Year Forward View<sup>1</sup>, we need to recommit to a publicly funded NHS. It must be fit for the 21st century, and built around a vision which can enthuse the public and NHS staff alike.

The Forward View has given us the foundations. The Sustainability and Transformation Partnerships (STPs) have begun the long journey of bringing NHS services and social care together as integrated systems, while the 50 vanguard sites2 have shown that new forms of organisation and delivery can provide better services.

However, while there are inspiring examples of new approaches to delivering care, the current reform programme is struggling to deliver the systemwide change that everyone knows is needed:

- · Integrated care is not happening on anything approaching the scale required. There are still barriers between service users and staff, community services and hospitals, physical and mental health, and health and social care
- Debate is mired in where care is delivered, rather than focussing on the nature of the care itself
- The pace of technological innovation is too slow, particularly when it comes to adapting care to consumer technology
- · Primary care is expected to alleviate the pressure on hospitals, even though it is already overwhelmed
- The relationship between commissioners and providers is still too adversarial and transactional to transform care.

The central message is not new - the NHS needs to move from being a treatment service to one which keeps people well and maximises their ability to look after themselves. To do this we need a profound change in culture so that each citizen is

seen and cared for in the context of their family, neighbourhood and community. We are assets to be liberated, not problems to be fixed. This means enabling everyone to contribute to their own health and the wellbeing of their communities.

We knew from our conversations that others shared our belief that to make the vision of integrated, person-centred, community-focussed care a reality, a new way needed to be found to free the talent, creativity and commitment of those working in health and care.

So we formed the Industry Coalition Group to develop a new approach and start a wider conversation around how we can build an NHS for the 2020s and beyond. It is made up of clinicians and senior leaders in hospitals, primary care, the central bodies, charities and the private sector. This report is the outcome of the coalition's work.

Central to this report is a refreshed model for primary care, with new Principal Care services co-ordinating a local response to the health, social and pastoral needs of their communities.

We have developed two examples of how this cultural revolution may be realised - care during the first 1,000 days of life and the last 1,000 days. This builds on the idea of New Zealand's Brian Dolan and others to focus on the last 1,000 days.

Maternity and infancy profoundly affect our life chances and lifetime consumption of healthcare. Giving every child a strong start is morally right, economic common sense and good for the NHS.

The last 1,000 days crystallise the issues of choice and empowerment, how care can maximise the quality of life rather than simply its length, and how to get the most value from healthcare resources.

The first and last 1,000 days have common ground, in that far fewer people are born and die at home than people wish. This is an example of people being prevented from making decisions about their lives.

Over the coming weeks and months we will engage with leaders across healthcare to promote these ideas, so that individual organisations and STPs - particularly those pursuing Accountable Care Systems can identify potential solutions to their challenges.

We are grateful for the commitment of the Industry Coalition Group and the innovative solutions they have proposed. We are particularly grateful to Sir William Wells, chair of The Practice Group, for his advice throughout the 2,000 days project.



Natalie Doualas Chief Executive Healthcare at Home



Mike Bell Chair **Industry Coalition Group** 

- https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf
- https://www.england.nhs.uk/ourwork/new-care-models/vanguards/care-models/care-homes-sites/



# Members of the Industry **Coalition Group**

The Industry Coalition Group was convened and funded by Healthcare at Home in response to a discussion at the Cambridge Health Network. Healthcare at Home had challenged the industry to come together to think differently, and a number of people came forward who wanted to respond.

Members shared their knowledge and insights. The findings of this report do not necessarily represent the views of individual members or their organisations.

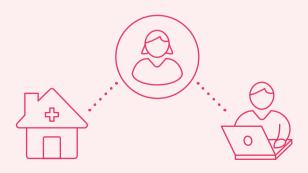
To learn more about the group's work or discuss how to put these ideas into practice, please contact mike.bell@zpb-associates.com.

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- Professor Sir Jonathan Asbridge, Clinical Director, Healthcare at Home
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- > Richard Vize, ZPB Associates and report author

# BUILDING THE 21<sup>ST</sup> CENTURY NHS: PEOPLE, STAFF AND CREATIVITY ARE THE KEY TO CHANGING CARE

The following seven principles are the foundation of an efficient and caring NHS.

- Person-centred care must be at the heart of every NHS decision and action.
- Person-centred care means taking every opportunity to maximise our ability to manage our own health. The NHS needs to focus on what we can do, not just try to fix what we can't.
- NHS leaders need to see joy and fulfilment in the workplace as key to delivering person-centred care and nurturing innovation.
- Care services must stop being health and safety police, and take a more balanced approach to risk, to empower staff and let people live the lives they want.
- Clinicians and managers need to be taught how to think digitally so they develop their own solutions using consumer technology. Online and face-to-face services should be integrated.
- Where possible there should be direct access, including digital access, to community services.
- The costs, benefits and practicalities of developing care at home need to be understood and debated.





# Where we are

Problems are outrunning solutions.

Building integrated systems around the needs of populations is at the heart of the Forward View, but financial and other short-term pressures are diverting STPs from this goal. Hospital debt is dominating decision-making.

Primary care is struggling. The National Audit Office says government plans<sup>3</sup> to increase the GP workforce are at risk<sup>4</sup>, 12 per cent of GP posts are unfilled<sup>5</sup>, and the average waiting time for a GP appointment has jumped to around two weeks6. In 2016 a record 92 practices shut<sup>7</sup>.

### WE NEED MORE STAFF WORKING IN A MORE FLEXIBLE CULTURE

Workforce now rivals funding as the most serious NHS problem8, with tens of thousands of vacancies, a morale crisis, staffing growth failing to keep pace with demand, and signs that the number of nurses is starting to fall again9.

The 26,000 additional clinicians since 2012 have been outstripped by 62,000 more posts, so vacancies have climbed.

The NHS is unattractive to today's workers; the most common reason for nurses quitting is inflexible working conditions, not pay. The rigid professional and structural divisions of the NHS are archaic compared with the rest of the economy. The Future Workplace<sup>10</sup> survey found that employers need a collaborative environment to attract and retain highcalibre staff.

Uncertainties about Brexit are jeopardising the recruitment and retention of EU staff.

# **TECHNOLOGICAL CHANGE** IS LEAVING THE NHS BEHIND

While digital technology is now integrated into our work, leisure and consumption, the NHS has failed to exploit it to improve access, quality and experience, and save

Staff can be resistant to using consumer technology to deliver healthcare. DigitalHealth.London highlighted<sup>11</sup> a US survey exposing differences between doctors and the public about whether patients should be empowered to use technology<sup>12</sup>. While 39 per cent of people said they would like to use smartphone apps to self-diagnose non-life-threatening medical conditions, just 18 per cent of physicians agreed.

Only 58 per cent of physicians thought that "new technology must be mastered to remain up-to-date".

Private sector online health services are challenging the primary care business model, with apps based on artificial intelligence providing 24/7 access at acceptable cost.

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**12%** \$

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2 weeks 1

average waiting time for a GP appointment.

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# Where we need to be

A person-centred future.

#### THE KEY GOALS

Don Berwick and the Institute for Healthcare Improvement proposed the Triple Aim<sup>13</sup> of improving patient experience and population health while reducing per capita cost. In 2015 Rishi Sikka, Julianne Morath and Lucian Leape turned this into the Quadruple Aim14 with the addition of bringing joy and fulfilment to the workplace. This is a robust set of goals which unite the interests of the public, clinicians, managers and taxpayers.

"The challenge is to redesign the system to respond to individual need while maximising our ability to look after ourselves."

# **FULFILLING OUR POTENTIAL** TO MANAGE OUR HEALTH AND CARE

Making us partners in our own care, by encouraging us all to take greater responsibility for our health and wellbeing, is essential ethically and economically. We have the right to make informed choices, and well-informed people often choose cheaper, less invasive treatments.

The challenge is to redesign the system to respond to individual needs while maximising our ability to look after ourselves.

The healthcare system needs a sophisticated understanding of each person, recognising that we have both biological and acquired potential. While biological potential will decrease as we age, acquired potential of knowledge and experience will grow. But health and social care are focussed on patching up or coping with decreasing biological potential rather than exploiting acquired potential. So the system has a deficit model of citizens looking for what's no longer working and what we can't do rather than maximising and using what we can.

Realising the potential of individuals and communities will create a shift in the NHS from a deficit approach to its resources - we are short of these so we need more of them - to an asset-based one - what resources do we have and how can we use them?

Maximising people's independence means shaping services around their needs rather than making them fit in with the supply of services. At the moment people give birth and die in hospital when they would prefer to be at home, have needless hospital visits, have to pester the GP to access virtually any service. and have to take time off work for an appointment when they would prefer a smartphone videoconference.

#### A NEW ATTITUDE TO RISK

Every day, individuals make informed decisions about the risks they are prepared to take, but health and social care too often take these decisions out of our hands. Poor risk management wastes

Care homes residents are discouraged from moving around because of the risk of falling-safe immobility is prioritised over activity, even at the cost of physical and mental wellbeing.

A balanced approach to risk management is a mark of a well-led team. A risk-averse culture is inimical to joy in the workplace, because it stops staff doing the right thing.

Care services must stop being health and safety police and help people live the life they want.

Poorly designed regulation is one of the drivers of excessive concerns about risk, which in turn stifles innovation. The regulatory regime must encourage a balanced approach to risk.

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# **DEVELOPING CLINICAL CARE AT HOME**

The home should be the starting place for care. It offers many advantages for people, staff and the system. It maximises independence and wellbeing, stops people's time being wasted, gives people control over their environment, reduces infection risks and removes the stress and anxiety of travelling to and being treated in hospital. It replaces the feeling that life is now focussed on illness and hospital with the experience of medical treatment fitting around normal life.

For NHS staff it means treating people who are less anxious and disorientated and better able to cope.

It reduces pressure on beds and hospital facilities, which allows wards and outpatient departments to focus on those who need to be there, and helps join up hospital and community teams.

This would be a profound change for the NHS, requiring new ways of thinking, training, organising and working. The costs, benefits and practicalities of developing care at home need to be understood and debated.

# **BRINGING JOY AND FULFILMENT** TO THE WORKPLACE

A proxy for the joy and fulfilment of work - the fourth part of the Quadruple Aim - is staff engagement. As the King's Fund notes<sup>15</sup>, factors that improve staff engagement include good support from managers, feeling the job makes a difference, having a clear objective and being involved in decisions. West and Dawson (2012) found that staff engagement improved experience and reduced infection and mortality rates.

Over the last five years the annual NHS staff survey<sup>16</sup> shows modest improvements on several measures, yet just 59 per cent of staff "look forward to going to work". Around 74 per cent are "enthusiastic" about their job, 52 per cent are involved in deciding changes and 53 per cent are satisfied with the recognition they get. Barely half are happy with the opportunities for flexible working.

The pursuit of joy and fulfilment in the workplace is the most effective antidote to the morale crisis, building on the sense of professional pride and vocation that brings so many people into healthcare. It depends on outstanding leadership, collaborative and supportive multidisciplinary teams, and staff being allowed to do the jobs they trained for rather than administer the system.

# **PERSONALISATION THROUGH INNOVATION - BRINGING TOGETHER 'HIGH TOUCH' AND 'HIGH TECH' CARE**

While workforce and integrating technology into care are two of the biggest challenges facing the NHS, they are seen as separate. But technology is part of the answer to staff shortages.

One way of thinking about this is the idea of high touch, high tech care, an expression more common in the US. The aim is to ensure timely human interventions where necessary, while maximising people's independence, such as using simple equipment plugged into a smartphone to monitor someone's condition and a clinical team responding to the information.

This avoids pointless check-ups and gives clinicians more time to care. So automation encourages personalisation. The difficult part is not the technology, but building the support systems around it.

Where high touch care is needed, the care setting should be appropriate, including in the home.

Oxford Health's telepsychiatry service17 found some staff were initially reluctant to use it, but engaging with them before and during the rollout helped ensure it was judged a success by staff and service users. A West Midlands Academic Health Science Network<sup>18</sup> study found that poor understanding among doctors, nurses and commissioners of what technology could offer was holding back adoption of simple tech such as apps to help manage longterm conditions.

Clinicians need to overcome 'same room syndrome' - the feeling that a consultation is not effective unless it is face to face. A smartphone videoconference can be more convenient and timely and just as effective.



# **MAXIMISING THE** BENEFIT OF HEALTH TECH

Doteveryone<sup>22</sup> - Martha Lane Fox's organisation dedicated to spreading the benefits of the internet - offers powerful concepts that should underpin health technology, including:

- · Map the ideal journey of a patient's data, so managers can work through the necessary permissions, consents and protections
- Design technology to meet the needs of the people who need it most, not the most people. If a service can work for an older person with multiple conditions or a homeless teenager, it will work for everyone
- Prioritise reusable, scalable technology - the public sector still tends to buy systems that are difficult to scale, maintain and replace. Procurement should encourage open standards and open source
- Ensure information infrastructure supports flexibility, enables diverse services and is suitable for tomorrow as well as today. Good infrastructure consists of loosely joined small pieces, enabling updates, evolution and changes of providers and tools.

doteveryone.org.uk

"Technology should be used to connect people, especially to empower them to manage their own care."

**Paul Bate** 



- 15. https://www.kingsfund.org.uk/sites/files/kf/field/field\_publication\_file/leadership-for-engagement-improvement-nhs-final-review2012.pdf
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- 19. https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/550866/Wachter\_Review\_Accessible.pdf

US physician and technology expert Robert Wachter's review<sup>19</sup> of NHS digital strategy recommended that digital education be improved for all health professionals. The announcement of the Digital Academy<sup>20</sup> and the push to make "every nurse an e-nurse21" are a start, but this sort of training needs to encompass hundreds of thousands more staff.

Clinicians and managers need to be taught how to think digitally so they develop their own solutions using consumer technology. NHS England is starting to adopt a more open-minded approach, such as clinicians using WhatsApp's encrypted messaging service, but it can do more to create a permissive environment.22

Routine use of artificial intelligence (AI) in the NHS is still some years away, but digital literacy needs to be built up now so there is a receptive environment for AI in the future.

Seventy per cent of older people's care homes do not provide internet access. With around 420,000 people living in care homes, that is hundreds of thousands of people without access. Apart from the obvious benefits, putting WiFi into care homes would help older people manage their health and improve safeguarding and care standards.

# **DIRECT AND DIGITAL ACCESS TO COMMUNITY SERVICES**

The rigid organisation of NHS services needs to adapt to changing technology and social attitudes.

A digital generation will expect multiple routes into healthcare based on their own convenience and the use of smartphones. Online triage has a major role to play in ensuring people access services appropriately. It will get people to the right service, improve direct access and reduce unnecessary appointments.

The NHS should allow direct access, including via digital platforms, to services such as talking therapies, physiotherapy and community nursing.

# **MAKE COMMUNITY SERVICES BIGGER, NOT HOSPITALS SMALLER**

When the Forward View was published there was optimism that prevention and early intervention would cut demand for hospital beds. But with hospitals typically running occupancy rates of 90-95 per cent<sup>23</sup> there is now no prospect of substantial reductions.

But while many people could be cared for in other settings, most STPs have not yet developed plans for investing in rehabilitation, home-care and intermediate care to make this happen. The King's Fund study of reform in Canterbury, New Zealand<sup>24</sup> shows it is possible to cope with rising demand without expanding hospital services if there is investment in fast, integrated community services.25

#### **UNDERSTANDING VALUE**

The NHS needs a more sophisticated understanding of value. For example, there is a big difference between value and efficiency. RightCare data uncovered a fiftyfold variation in use of knee arthroscopy<sup>26</sup>. While it seemed efficient, the service was overused, often ineffective and sometimes harmful, so it was low value.

Muir Gray's outcome-focussed Triple Value<sup>27</sup> aims to increase the benefit from the resources available. The NHS is promoting the Triple Value approach in its RightCare programme<sup>28</sup>. The three value types are:

Allocative - have resources been allocated to different groups equitably and in a way that maximises value for the whole population?

Technical - improving the quality and safety of care. NHS Improvement's Get It Right First Time<sup>29</sup> programme is an excellent example.

Personalised - ensuring decisions are based on the best current evidence, an individual's clinical condition, and their values, such as what outcomes are important to them and what value they attach to the risks and benefits of different treatment options. This comes back to empowering people.



# **CONSULTANTS IN THE** COMMUNITY

The Symphony Vanguard<sup>25</sup> in South Somerset aims to join up the services of Yeovil District Hospital Foundation Trust, local GPs and Somerset County Council for its population of 200,000. It focusses on caring for people with multi-morbidities and improving health through self-management, identifying crises early and operating a single care pathway. Care led by hospital consultants extends into the community.

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# The touchstones of good care

People, staff and creativity.

People-centred care, motivated staff and a culture of innovation are how demand will be managed and the NHS will become clinically and financially sustainable. We believe three ideals should underpin the next phase of NHS development:

# 1. PEOPLE-CENTRED CARE **MUST BE AT THE HEART OF EVERYTHING THE NHS DOES**

The health service needs to deliver the NHS Constitution's<sup>30</sup> promise to put people at the heart of everything it does. This means involving the public in decisions about services and their own care, and putting people at the forefront of everything from clinical training to the work of the STPs.

# "The health service needs to deliver on the NHS Constitution's promise to put people at the heart of everything it does."

Care should be rooted in the home and community. 'Home first' care should be a whole life approach which gives children the best start, and throughout life maximises people's independence, life quality and ability to manage their own health. That is how to minimise hospital admissions.

People's time is precious. The NHS must not squander it through inefficiency and thoughtlessness.

# 2. JOY AND FULFILMENT MUST **BE BROUGHT BACK TO THE** WORKPLACE

Motivated, respected and empowered staff will deliver safe, high quality, personcentred care. Too often the relentless pressures of demand and budgets are distorting leadership behaviours.

The response to a tough environment needs to be an ever greater focus on outstanding leadership.

The role of GPs needs to be reformed so they spend less time managing demand for everyone else and have more time to care for those who need them.

Staff time is also precious. Care systems must not waste it through burdensome administration, unnecessary tasks, poorly managed meetings or having to constantly seek approval for decisions.

# 3. LEADERS MUST CREATE THE CONDITIONS IN WHICH IMPROVEMENT AND INNOVATION THRIVE

Motivated, empowered staff seeking to put people at the heart of everything they do will find better ways to deliver care. The best care has the goal of service improvement, not just delivery.

An innovative culture will instinctively put people and populations, rather than buildings and organisations, at the heart of decision-making. It will give staff the skills and freedom to use technology - notably low-cost consumer technology - to provide flexible, person-centred care.







# **Building a Principal Care service**

Putting our ideas into practice.

### **DEFINING PRINCIPAL CARE**

The World Healthcare Organization31 (WHO) describes primary care as a key process in the health system. It is first contact, accessible, continued, comprehensive and coordinated care.

It sees the GP as the only clinician who operates at every level of care, including prevention, detection, diagnosis, management of disease and complications, rehabilitation, palliative care and counselling.

"We envisage Principal Care operating within accountable care systems, serving populations in the region of 50,000"

The WHO sees the goal for primary care as better health for all, including reducing social inequalities in health, organising health services around people's needs and expectations, involving people in their care and integrating healthcare into wider public policy goals.

Principal Care is based on the WHO description, with broad-based, collaborative networks providing the first line of care, and GPs at the heart of that network.

We envisage Principal Care operating within accountable care systems, serving populations in the region of 50,000. That size has been shown to work well for developing a deep understanding of population health needs and for service integration.

# WHAT A PRINCIPAL CARE **SERVICE MIGHT LOOK LIKE**

The service would be jointly commissioned by the CCG and local authority (see the legal framework below), with each service tailored to the needs of its community. Alongside statutory health and social care, Principal Care services would act as a locus for a wider range of pastoral services such as debt, housing and employment advice.



Governance arrangements would ensure a voice for social care, general practice, acute physicians, community nursing, pharmacy, addiction services, mental health, perinatal care and child health, sexual health and therapy services.

There would be a single, easy to use digital interface. Digital triage would direct people to the appropriate service and promote self-help at every opportunity.

Services could be accessed directly unless this was inappropriate.

Online and face-to-face services would be integrated, so service users could access services over their smartphone or computer. This would include, for example, GP consultations, computerbased psychological therapies, mental health crisis support and sexual health advice. Online hours would be as long as practicable.

GPs would be at the centre of the service, managing, providing and coordinating care. There would be a single care record.

Every contact would maximise self-care, such as pharmacists supporting the taking of medication, home visitors supporting physical activity and mothers being supported in breastfeeding their children. Signposting to non-medical interventions such as exercise and social contact would be key.

There would be a single, easy to use digital interface. Digital triage would direct people to the appropriate service and promote self-help at every opportunity. Services could be accessed directly unless this was inappropriate.

Online and face-to-face services would be integrated, so service users could access services over their smartphone or computer.



# **DELIVERING PEOPLE CENTRED** CARE IN THE COMMUNITY

People should be supported to live well. with access to social, pastoral and medical care, including doctors, nurses, therapists, care navigators and advisers on issues such as debt, housing and employment, which are major contributors to mental

Personal health budgets for people with long-term conditions should be used more widely, promoting independence and encouraging coordination with services delivered through a personal social care budget.

"Principal Care needs a deep understanding of the local community. It requires primary, acute, community, mental health, social care, commissioners, local *authorities, the voluntary* and community sector and private service providers to buy into a single action plan, built around population needs and risks."

#### Jane Milligan





# **PRINCIPAL CARE - THE LEGAL** FRAMEWORK<sup>32</sup>

to the Industry Coalition Group

The main commissioners of health and social care services are NHS England (primary care and specialised services), clinical commissioning groups (acute, community and mental health services as well as delegated commissioning powers for primary care) and local authorities (social care and public health

The number of commissioning bodies often leads to fragmented commissioning, but there are legislative flexibilities that allow integration through joint decision-making and pooled budgets.

There are certain contracts that commissioners have to use when they are buying clinical services. For example, the NHS Standard Contract must be used when buying acute, community or mental health services. Highly regulated primary care contracts (General Medical Services, Primary Medical Services or Alternative Provider Medical Services) must be used for primary care. However, the NHS contracting environment is beginning to recognise the importance of emerging accountable care models.

Under a section 75 agreement, NHS commissioners can delegate functions section 75 agreement allows NHS bodies and local authorities to integrate commissioning functions and pool budgets.

In August 2017, NHS England published a draft Accountable Care Organisation contract to help implement the integration of general practice with other health and social care services, and to change the payment system, moving to a whole population payment approach. The contract envisages two levels of integration:

- Partially-integrated where core primary care services are not commissioned
- Fully-integrated where primary care services are commissioned under the ACO contract.

commission a 'fully-integrated' ACO contract, adapted to integrate core primary care services with social and other services. This would allow a Principal Care system to be implemented. Any CCG wishing to use the draft ACO contract requires NHS England's permission.

A CCG could also commission a mixture of primary care and social services, under an APMS contract, where NHS England and a local authority have delegated those commissioning functions to a CCG. This is another option for

So there are a number of commissioning options for a Principal Care system.

# **BRINGING JOY AND FULFILMENT** TO THE PRINCIPAL CARE WORKPLACE

The Principal Care approach would free professionals to perform the roles they trained to do. GPs would be able to focus their skills on the people who need them most - providing, coordinating and integrating their care, while physiotherapists, counsellors and others would be empowered to manage their own services

# **CREATING A CULTURE OF INNOVATION**

The greater sense of ownership that would be felt by staff running direct access services would stimulate new ways of thinking about their population's health needs and providing services.

By concentrating on people with complex needs. GPs would develop new pathways in coordination with other services in the community and hospitals.

Building on relationships with local government and the voluntary sector to coordinate healthcare with services such as debt, housing, addiction and relationship advice would help address social determinants of health which drive demand for primary care.

# THE ROLE OF STPS IN BUILDING **PRINCIPAL CARE SYSTEMS**

If STPs focussed on building services around their communities through the Principal Care approach they would improve access, encourage collaboration across professional boundaries and allow staff to deliver the services for which they trained.

In contrast to reconfiguring nonspecialist hospitals services, which some STPs are still pursuing despite scant evidence35 that such changes are likely to save money or improve quality, Principal Care can be pursued with the support of local people, politicians and clinicians.



# **DEVELOPING POPULATION HEALTH MANAGEMENT**

disciplinary teams working around the needs of defined populations.

Launched in 2015, Primary Care Home now has more than 200 sites serving eight million people. It is based on populations of around 30,000 to 50,000, which the NAPC believes is the optimum size to let change happen at a

There is a focus on personalisation of care. Clinical and financial drivers are unified through a capitated budget with shared risks and rewards.

scrapping the archaic system of nurses needing GP approval for changing a home dressing is saving a typical nursing team and GP practice eight hours a week. That success is now stimulating changes to other pathways.



"Principal Care is based around the design of systems which integrate care around population health outcomes. It's an approach to align providers of care around a common purpose with aligned incentives."

Dr Nav Chana



<sup>33.</sup> http://napc.co.uk/primary-care-home/

<sup>34.</sup> https://www.kingsfund.org.uk/sites/default/files/media/Dr%20Nav%20Chana%20and%20Michelle%20Bull.pdf

https://www.kingsfund.org.uk/publications/reconfiguration-clinical-services/main-findings



# The first 1,000 days of life

Putting our ideas into practice.

# THE CRITICAL IMPORTANCE OF THE BEGINNING OF LIFE

Maternity and the first three years of our lives influence life chances and future healthcare consumption.

The scientific committee of the European Board and College of Obstetrics and Gynaecology concluded36 that a baby's development in the womb has a major impact on adult health and disease risk, and stressed the importance of addressing maternal lifestyle risks such as smoking and malnutrition.

The impact of social factors on life chances is stark: the Maternal, Newborn and Infant Clinical Outcome Review Programme<sup>37</sup> found that pregnancies of UK women living in the most deprived areas were over 50 per cent more likely to end in stillbirth or neonatal death compared with the least deprived areas.

Babies of Black and Black British, and Asian and Asian British, ethnicities had the highest risk of perinatal mortality, with rates of 9.9 and 8.7 deaths per 1,000 total births respectively, compared with an overall rate of 5.9 deaths per 1,000 births.

The Equalities and Human Rights Commission<sup>38</sup> highlighted evidence that poor social and cognitive skills in childhood had a big impact on social outcomes in adulthood, such as being in trouble with the police and having poor physical or mental health.

The first two years of life are key to brain development. Scans reveal differences in brain size between children who have had a healthy upbringing and those who have been neglected.

Children's early years have an important influence on their future diet.

# **DELIVERING PERSON-CENTRED CARE AT BIRTH**

NHS England's National Maternity Review39, which calls for personalised care centred on the needs and decisions of the woman.

her baby and her family, found 10 per cent of women would prefer a home birth. Yet 2.3 per cent of births in 2015 took place at home<sup>40</sup> - barely more than the 1.7 per cent who did not give birth either at home or in a healthcare facility but somewhere else, such as a car.

"It doesn't happen that much here, because we are a risk averse society."

**Mike Bell** 



Another 55 per cent of women would prefer to give birth in a midwifery unit, while only 25 per cent wanted to give birth in an obstetric unit. Yet 87 per cent of births actually took place in obstetric units, and just 11 per cent in midwifery units.

Highest risk of perinatal mortality

9\_9 and 8\_7 per 1,000 total births

For babies of Black and Black British and Asian and Asian British ethnicity compared with an overall rate of 5.9 per 1,000 births.

of women would prefer a home birth. Yet 2.3% of births in 2015 took place at home.



<sup>36.</sup> https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4402443/

https://www.npeu.ox.ac.uk/downloads/files/mbrrace-uk/reports/MBRRACE-UK-PMS-Report-2014.pdf

https://www.equalityhumanrights.com/en/publication-download/research-report-7-early-years-life-chances-and-equality-literature-review https://www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf

<sup>40.</sup> https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/bulletins/birthcharacteristicsinenglandandwales/2015

The National Institute for Health and Care Excellence (NICE) advises<sup>41</sup> that the outcome for the baby of a low risk woman giving birth to a second or subsequent baby at home or in a midwifery-led unit is no different to an obstetric unit. For lowrisk women having a first baby, a planned homebirth has a small increased risk of an adverse outcome.

"Cultural norms and social pressures play a role in whether a mother is likely to breast feed."

#### **Tina Hickson**



Rates of planned home birth<sup>42</sup> range from 0.1 per cent in Sweden to 20 per cent in the Netherlands. Benefits include lower rates of maternal morbidity, such as postpartum haemorrhage, and lower rates of interventions such as an episiotomy. Women who have planned a home birth have high rates of satisfaction because they are more comfortable and feel in control.

Despite good intentions around increasing the number of home births, risk assessments channel mothers to hospitals. Services are designed around what rarely happens rather than what is most appropriate for each mother. This takes away choice, medicalises pregnancy and turns mothers into patients. For planned births, obstetric units are over 50 per cent more expensive<sup>43</sup> than home births.

# PERSON-CENTRED MATERNAL **MENTAL HEALTH CARE**

The Centre for Mental Health<sup>44</sup> says one in five women experience mental health problems during pregnancy or the year after birth. According to NICE<sup>45</sup>, depression or anxiety affects around 12 per cent of pregnant women and 15-20 per cent of women in the first year after childbirth. Psychosis affects between one and two in every 1,000 women who have given birth.

Women fear disclosing distress to clinicians, and many who do are already in crisis. Many doctors do not know how to respond so they rely on prescribing. Women referred for psychological therapies can have long waits.

In 2016 NHS England announced a total of £40 million for 20 areas46 to develop perinatal mental health services. More funding is expected.

# **ENCOURAGING SELF-RELIANCE** THROUGH BREASTFEEDING

The UK has one of the world's lowest breastfeeding rates<sup>47</sup>, with pronounced differences between ethnic groups. In the UK only 80 per cent of women start breastfeeding, dropping to just 25 per cent at six months. In 2016 just 0.5 per cent of mothers were breastfeeding at 12 months.

Over 90 per cent of Black African and Black Caribbean mothers start breastfeeding, compared with over 85 per cent of Indian and Bangladeshi mothers, 75 per cent of Pakistani mothers and 67 per cent of white mothers.

In Scandinavia<sup>48</sup> 98 per cent of women breastfeed immediately after birth, and 80 per cent are still doing so at six months.

The advantages of breastfeeding include stronger bonding between mother and child, providing antibodies, supplying hormones that help the baby's development, fewer infections, a lower risk of obesity and lower susceptibility to allergies. Personalised medicine - the big promise for the next wave of life science innovation - is already here, but we are failing to make use of it.

Advantages for the mother include a lower risk of developing ovarian and breast cancer and a lower risk of diabetes in older age.

Other services should encourage parents to manage the health of their children. Small changes matter. In Coventry and Warwickshire, community services want to transfer responsibility for recording children's height and weight to parents. Officially a nurse should do it, but parents taking it on would encourage greater responsibility. They could be supported by other mums, pharmacies and apps, which would store and transmit the information.

55%

of women would prefer to give birth in a midwifery unit.

87%

of births actually take place in obstetric units, and just 11% in midwifery units.

Rates of planned home birth range from

0.1% in Sweden to

20%

in the Netherlands.

Benefits include lower rates of maternal morbidity.

Women who have a planned home birth have high rates of satisfaction because they are more comfortable and feel more in control.

# COMMUNITY SUPPORT FOR **BREASTFEEDING**

Baby cafés are breastfeeding clubs led by mums and supported by health professionals. They promote the message that breastfeeding is important for emotional bonding, reducing child mortality and boosting health in adulthood.

 $<sup>\</sup>begin{array}{ll} 41. & https://www.nice.org.uk/guidance/cg190/chapter/Recommendations\#place-of-birth \\ 42. & https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4399594/ \end{array}$ 

<sup>43.</sup> http://www.bmj.com/content/344/bmj.e2292

<sup>44.</sup> https://www.centreformentalhealth.org.uk/Handlers/Download.ashx?IDMF=9c9ea879-a7bf-4f0a-9ee8-e32ee697d265

<sup>45.</sup> https://www.nice.org.uk/guidance/cg192/chapter/Introduction

<sup>46.</sup> https://www.england.nhs.uk/mental-health/perinatal/community-services/

<sup>47.</sup> http://childofourtimeblog.org.uk/2015/04/breastfeeding-and-ethnicity/ 48. https://www.britishscienceassociation.org/news/breastfeeding-rates-in-uk-are-the-lowest-in-the-world



# A HOLISTIC APPROACH TO PREGNANCY, **BIRTH AND EARLY DEVELOPMENT**

#### PRECONCEPTION ADVICE

Croydon has high teenage conception rates, so family nurses visit schools to tell girls about the impact of pregnancy. This includes getting them to wear a 'pregnancy suit' with heavy bump.

Preconception support includes advice on diet and supplements and expectations of maternity care. Advice is accessed online, through children's and community centres and pharmacists.

#### SUPPORT DURING PREGNANCY

Pregnancy support can be accessed through self-referral or the GP. It is provided locally and built around births at home or birth centres, with hospital reserved for high-risk delivery.

Staff help parents prepare for what it will be like to have a child and understand issues such as the importance of parental bonding in emotional and neurological development.

#### 0-2 YEARS AND POSTNATAL CARE

The Mental Health Liaison Service provides perinatal care, with a focus on identifying and supporting postnatal depression. Cases of psychosis are dealt with as an emergency, with admission to a mental health unit. Support for moderate or mild postnatal depression includes GPs and health visitors, monitoring, and antidepressants when appropriate.

There is a concerted effort to promote bonding and social development. Interventions to promote bonding and prevent neglect include:

- · Identifying attachment issues and resolving them quickly
- · Education and parenting groups
- Encouraging male presence and attachment, especially if the mother has postnatal depression
- · Addressing problems with drugs, drink and domestic violence

#### **BRINGING TOGETHER COMMUNITY AND ACUTE SERVICES**

The goal is to build a 'Paediatric Village', bringing together community and acute paediatricians. It will help them develop each other's care and share good practice. The challenge is changing the way people think about their role.





# The last 1,000 days of life

Putting our ideas into practice.

# **TOUCHSTONES** FOR END OF LIFE CARE

For people reaching the end of their lives, the touchstones of good care are:

- · Remembering a person's time is precious
- · Maximising independence and life quality for as long as possible - including maximising fitness by keeping hospital stays short
- · Supporting people to decide for themselves about their lives and care
- Minimising pain, distress and anxiety - including minimising emergency admissions
- · Treating each individual with dignity and respect.

"Patients should be empowered to have choice and control over what happens to them through their last 1,000 days, with advanced care plans becoming as standard as wills. We should work hard to not keep people 'safe' at the expense of everything that matters to them"

# Liz Sargeant



Of course, end of life care must meet the needs of people at any age. For example, the NHS needs to meet the needs of someone who is terminally ill with a young family, or a mother with a terminally ill child, as well as those of a frail older person.

The approach to end of life care has become so distorted that it is easier to get an emergency admission than to have a care worker with you at home for three days, even though the latter is cheaper.

Care of older people is oriented towards keeping them 'safe' rather than understanding their goals and priorities and maximising their independence of thought and action. The narrative needs to change from: "What's the matter with you?" to: "What matters to you?".

Hospital care in the final 90 days of life averages around £4,600, with costs rising steeply in the last 15 days. Emergency admissions are a major factor. So, although the NHS is investing heavily in end of life care, it is not doing it in a way which maximises wellbeing and quality of life or avoids unnecessary strain on emergency services.

### **REDUCING HOSPITAL ADMISSIONS**

Over 65s use A&E four times more than younger people. Between 2010-15 there was an 18 per cent increase in emergency hospital admissions for older people. Yet less than one per cent of spending on older people is dedicated to reducing admissions.

Care should be 'home first', with nurses, therapists and geriatricians maximising independence and quality of life while minimising time in hospital.

Investment in community facilities, including short-term residential care, would provide a non-medicalised environment and reduce the need to be admitted.

Carers also need greater support. They often have to call an ambulance because they do not know where else to turn. Investment in community services and giving people the information and reassurance they need could significantly reduce emergency admissions. With the right clinical oversight, much of this work can be done by support workers - it does

# **ASSESSING PEOPLE AWAY** FROM HOSPITAL

South Warwickshire FT and Warwickshire County Council aim to assess all people with ongoing need, including the frail and elderly and those with cognitive problems and dementia, out of hospital. There are three pathways in the 'discharge to assess' process:

- 1. Supported discharge a multidisciplinary team including social care was set up, the number of community beds was halved and the money was invested in care at home
- 2. Rehabilitation pathway those wanting to return home are given short-term community or residential home beds commissioned by the trust and council
- 3. People with the most complex needs - mainly frail elderly who are unlikely to return home are moved to a care home for continuing assessment over a short period. This is funded by the council and the trust.

The assessments deliver different outcomes to in-hospital assessments, with a significant reduction in perceived needs, such as for people with dementia.

not have to be a doctor or nurse. The six enhanced health in care home vanguards<sup>49</sup> have shown promise in reducing admissions from care homes to hospitals. They have increased the involvement<sup>50</sup> of GPs, district nurses, consultants and others in supporting residents, and home staff have had additional training and undertaken new roles. Tools such as the comprehensive geriatric assessment<sup>51</sup> are used to keep people well - rather than just react to ill-health.

Other care homes and local health systems need to build on these successes quickly. Home staff need the training and confidence to know when an ambulance is required and when a visit from a doctor or nurse for a minor illness would be better. Online consultations have an important role.

#### **GETTING PEOPLE HOME QUICKLY**

Hospital care of frail older people should maximise health and fitness and minimise length of stay.

Frailty teams need to work with ambulance paramedics to identify which of the people they are bringing in need support from the frailty team rather than emergency care, giving them faster access to specialists such as geriatric consultants and physiotherapists.

Getting people on a frailty pathway saves hospital resources and speeds up diagnosis, so hospital stays are shorter. The frailty team can start working on the discharge plan almost as soon as someone arrives while A&E staff can focus on true emergencies.

# **RECEIVING MAJOR TREATMENTS AT HOME**

Chemotherapy $^{52}$  can now be administered at home, opening up the possibility of other major treatments being delivered there.

At home, people feel more relaxed and in control of a procedure that takes several hours. They do not have the foreboding of travelling to hospital. They have privacy. They have a stronger bond with the medical staff because the clinicians are there for the duration rather than being called away. The home environment builds trust, while the reduced stress may mean people are able to continue treatment for longer.

The NHS should explore the benefits and costs of delivering other major treatments in the home or community settings.

#### **MENTAL WELLBEING**

The mental health of older people is paramount. They need to be supported through challenges such as bereavement, isolation and depression.

Empowerment is central to mental wellbeing. The London Borough of Barking and Dagenham<sup>53</sup> offers older people PAs to help them navigate the care system, assert their rights and maintain independence.

Technology has a lot to offer the mental health of older people, from keeping in touch with family and friends through social media to travelling the globe online and learning skills. Older people should be encouraged to embrace the online world as a significant part of their lives, which liberates them from physical constraints.

Health and care organisations must ensure couples are not separated, such as by being forced to go to different care homes or being unable to visit their partner in hospital. This is a human right.

Peer support also has a big impact. Councils such as the London Borough of Brent<sup>54</sup> have created communities of older people with dementia from the same ethnic background.

# **CHEMOTHERAPY AT HOME** - ONE WOMAN'S STORY

Gren was treated with chemotherapy by Healthcare at Home<sup>52</sup>. She says:

- "My consultant told me that home care was an option, so it seemed the best choice. The nurse explained what would happen and how it would work, so I felt comfortable with my decision.
- "The treatment lasted for eight hours, and the thought of having to travel to hospital and sit with people you don't know for that length of time was too much. Being in the comfort of your own environment that you can control - having a sandwich or a cup of coffee whenever you want it – meant choosing home care was a no-brainer."



https://www.england.nhs.uk/ourwork/new-care-models/vanguards/care-models/care-homes-sites/

<sup>50.</sup> https://www.kingsfund.org.uk/blog/2017/06/care-homes-building-promising-start http://www.bgs.org.uk/carehomes/campaigns/carehomes/questforquality

https://hah.co.uk/

http://careandsupport.lbbd.gov.uk/kb5/barkingdagenham/asch/pa\_home.page

<sup>54.</sup> http://www.cad-brent.org.uk/

# **RESPONDING TO PEOPLE'S CHOICES ABOUT WHERE THEY** WANT TO DIE

The charity Marie Curie<sup>55</sup> has exposed the chasm between where people want to die and where they are allowed to die. Fewer than 21 per cent of people die at home compared with 63 per cent who want to do so. Almost 55 per cent of people die in hospital even though only eight per cent wish to, and fewer than five per cent die in a hospice even though that is the choice of 28 per cent. Virtually nobody wants to die in a care home but almost 18 per cent do. The cost for a day of community care at the end of life<sup>56</sup> is £145 compared with £425 for a palliative bed day in hospital.

Living wills are important in making our wishes about how we wish to be treated towards the end of life clear. They can cover issues such as when to move to palliative care, and whether someone wishes to be resuscitated in certain circumstances. Living wills need to become a routine part of discussions about our care.

The new NHS app announced at the 2017 NHS Expo should make it easier for people to express their preferences. GPs, other clinical staff and nonclinical community workers need to provide encouragement and support to help us make these choices.

#### WE NEED TO TALK ABOUT DEATH

An obstacle to dying at home can be family. In the UK, death is still a taboo. People can go through their lives without seeing a dead body or being with someone as they die. We have sanitised death to the point where much of it is outsourced to the state.

This makes it difficult for people to embrace the idea of a loved one dying in their own home. They are uncomfortable with realities such as someone dying in their own bed, and worry about what to do when someone has died.

This may influence the wishes someone expresses, opting to die in hospital because they don't want to burden their family.

As part of enabling more people to die at home, we need a national conversation about death. This should include learning from ethnic minority communities that have a more open-minded and accepting approach to people dying.

# WHERE PEOPLE WANT TO DIE

Fewer than 21% of people die at home compared with 63% who want to do so.

Almost 55% of people die in hospital even though only 8% wish to.

Fewer than 5% die in a hospice even though that is the choice of 28%.

Virtually nobody wants to die in a care home but almost 18% do.



# The way forward

Putting person-centred care at the heart of the NHS.

The Principal Care approach offers local communities, providers and commissioners the opportunity to unite around a vision of healthcare which puts the individual and their community at the heart of decision-making.

Moving the conversation with the public away from costly, contentious plans for hospital reconfigurations which will take years to implement and towards the development of community services would help rebuild trust about the future of the NHS.

"Public involvement needs to include everyone – notably those who will be utilising services from young to old not just the usual voices."

**Dr Olivia Kessel** 



Principal Care draws on readily available resources. A relentless focus on encouraging self-help while freeing staff to do the jobs they trained for would empower service users and energise staff. At a time of extraordinary pressure, unlocking capacity needs to be at the forefront of change.



A similar approach is needed with IT assets. A great deal can be achieved by exploiting consumer technology, from information sharing to online consultations, underpinned by a single electronic record to ensure continuity of care.

A Principal Care approach would allow everyone in the system to unite around a single vision. Seeing everything from the service users point of view moves away from arguments about which organisation should deliver which service, or whether money should be in primary care or acute care, to putting experiences and outcomes at the forefront of every decision.

As we hope we have demonstrated through the lenses of the first and last 1,000 days of life, compelling stories soon stimulate fresh thinking about how to improve people's quality of life and independence. Freeing staff to innovate is the surest way to bring joy back to the workplace and to rekindle the sense of vocation which overwhelmingly motivates the healthcare workforce.

Recent encouragement to lead local health services as systems rather than separate organisations is a promising start, but it will only take root as a guiding value of the NHS and social care if organisations and teams unite around the interests of service users. Integrated, person-centred care will remain out of reach as long as decisions remain focused on bartering between organisations.

The regulatory, target and inspection regimes need to play their part, ensuring that success is measured by what is valuable to the individual.

So, as the NHS struggles to cope with rising demand and the continuing repercussions of the 2008 economic crash, a new approach is needed which liberates staff to care, exploits readily available technology and encourages us all to accept personal responsibility for our health. Principal Care can be a major contribution to that journey.

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Healthcare at Home has challenged the industry to come together to think differently, they provided resource, expertise and evidence to support this process.

Healthcare at Home is transforming healthcare

We're the UK's leading full service, clinical provider of healthcare out-of-hospital, wherever you are – at home, at work and in communities. People increasingly expect choice in all things. Healthcare is no different. As a team of specialists, we're committed to enhancing people's healthcare experience by providing exceptional clinical services that allow people greater and smarter options for access to healthcare.

Seeing the bigger picture. Collaborating. Innovating. This is what sets us apart.

We partner with public, pharmaceutical and private providers to deliver services that are essential for sustainable healthcare. For over 25 years we have delivered the highest standard of clinical care, covering multiple specialities, consistently working smarter to meet our customers' needs.

Healthcare at Home. Passionate about transforming healthcare.

For more information about our services and reports please visit our website: www.hah.co.uk

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