Change NHS

Submission by Yes to Life

Co-authors:

Dr Penny Kechagioglou MBBS (Honours), MRCP, CCT (Clin Onc), MPH, MBA, DBA, PG Dip Digital Health – Lead Advisor to Yes to Life on Integrative Oncology

Robin Daly – Founder & Chairman, Yes to Life

Introduction

In November 2024 the UK public were invited by Health & Social Care Secretary, Wes Streeting, to contribute ideas to rescue the NHS from its current downwards trajectory. "Our NHS is broken, but not beaten. Together we can fix it." This was the introduction to **Change NHS**, a once-in-a-lifetime opportunity to have our say, that we at **Yes to Life** immediately knew we had to respond to. Although there are no certainties as to what effect this unprecedented public input will have, we felt the need to express clearly the changes we would like to see, and to argue the case that these will provide solutions to many of the key ills affecting UK healthcare in the twenty-first century.

Having found the exercise very useful in clarifying our stance on various healthcare issues, we decided to make our submission public. It relates strongly to our **Charter for Oncology**, published earlier this year, which sets out the ethos for an entirely new relationship between those delivering and those in need of healthcare, one that opens up unlimited potential for rapid improvements in resources, methods and most importantly results, as well as approaches to prevention and health promotion that are currently totally absent from mainstream healthcare.

I hope you find our Change NHS submission of interest. Please do contact us if there is anything you'd like to know more about or discuss. And if you find you are in favour of our ideas and wish our Charter for Oncology to be seriously considered, please sign our petition and share it with friends and colleagues.
Yours

Robin Daly
Founder & Chairman

The Questions

Q1 What does your organisation want to see included in the 10-Year Health Plan and why?

Q2 What does your organisation see as the biggest challenges and enablers to move more care from hospitals to communities?

Q3 What does your organisation see as the biggest challenges and enablers to making better use of technology in health and care?

Q4 What does your organisation see as the biggest challenges and enablers to spotting illnesses earlier and tackling the causes of ill health?

Q5 Share specific policy ideas for change. Please include how you would prioritise these and what timeframe you would expect to see this delivered in.

The Answers

Q1. What does your organisation want to see included in the 10-Year Health Plan and why?

Yes to Life is a patient-led charity focused on improving Cancer care, but we are aware that many of our recommendations below are equally relevant to the treatment of most other types of chronic disease, which share many of the same common features and drivers.

No real change without cultural change

Lord Darzi's recent report highlights the many issues in UK healthcare that have driven the Change NHS initiative: These established problems include the rising demand for care and treatment costs, the delayed diagnosis and treatment of Cancer and other disorders, leading to high mortality or morbidity, patient dissatisfaction and loss of staff morale. The above challenges ultimately lead to the declining health of the population and demonstrate the inability of successive governments to effect change in the NHS to enable it to adequately respond to this complex health landscape.

Underpinning the resistance to change is the lack of genuine interest in both the patient and clinician voice. Engagement of these has long been a key objective in NHS plans, but the last 25 years has seen merely lip service paid in terms of a willingness to listen and adapt. The deep cultural shift that this requires has been neither appreciated nor adopted, resulting in very little progress. This leaves the NHS significantly out of step with parallel developments in society which have steadily moved towards increasing choice and autonomy. Patient-centred care, a concept more than 50 years old and long enshrined in the NHS Charter, is still barely discernible in Cancer care.

The NHS was built to respond to emergencies with a command-and-control structure, and it still delivers well when it comes to acute care. But the NHS model is entirely unsuited to meeting the many challenges of the predominant issues of our time, which are chronic conditions. The very structure and culture of the organisation excludes a fundamental appreciation of how to meet the broader needs of people with Cancer beyond emergency care, and so – as has been amply demonstrated – the NHS lacks the ability to make the necessary changes to improve Cancer care without outside assistance.

In parallel with the inability to deliver satisfactory care, we are also seeing the decimation of our NHS workforce. Continuous failure to meet the needs of patients takes a huge toll, and when coupled with an inability to take creative clinical decisions to improve the situation, leads to disillusion and burnout, and the resulting decline in 'discretionary effort' that Lord Darzi highlights.

Clinical judgement

Clinical judgement was always intended to be a key element of evidence-based decisions and must be returned to its rightful status if we are to see engaged clinicians and improving outcomes. Evidence-based medicine, despite its many virtues, has had the negative and unintended consequence of disempowering clinicians and constricting clinical decision-making by being over-prescriptive. Furthermore, the sources of evidence are, in the main, from outside the NHS, from artificially engineered trials, and are disconnected from the vast wealth of 'real world' clinical experience within the organisation

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The case for Integrative Oncology in the UK

Fortunately, a model of care that can successfully meet the broader needs of those facing the personal crisis of cancer – **Integrative Oncology** – is already quite well developed in other countries, and many of those skills already exist in the UK, although outside the NHS. Such a model of care has been proven to be cost-effective in various centres in the world such as the MD Anderson and Mayo clinics in the US and the Chris O'Brien Lifehouse in Australia, and to lead to better long-term clinical outcomes while reducing the burden on hospital care and improving productivity.

With almost half of cancers being preventable through lifestyle changes alone[1], the complete absence of skills and knowledge in oncology regarding lifestyle interventions highlights the stark mismatch between services and needs. There is an urgent need for primary, secondary and community care services to join up in Cancer care delivery, and to partner with charities and other organisations to deliver an Integrative model of care, one that combines evidence-based conventional, lifestyle and complementary medicine approaches to a degree far beyond anything currently in place in the UK. Prevention is ultimately where solutions lie, and such a model of care supports prevention and early diagnosis, as well as treatment and recovery.

Collaboration - at the heart of patient-centred care

A much broader, collaborative approach to providing care holds a key to delivering improved services and reversing the steep decline in staff morale. However, for this to be a reality, the NHS has to move beyond the 'red tape' , and to achieve 'integration' in Cancer care, requires clinicians and patients to work closely together with commissioners and policy makers, building relationships based on trust, respect, empathy and hope. This is a fundamental and urgently needed cultural shift.

This new, collaborative model of working, both within the NHS and with external providers, must be characterised by a willingness to learn on all sides – for the benefit of patients – enabling the NHS to evolve through an understanding of the progress and developments in health promotion, prevention, person-centred care and patient empowerment that have been achieved elsewhere. A modern, fit-for-purpose oncology service will require supportive oncology resources within or wrapped around oncology clinics, such as health coaches, dieticians, nutritionists, dedicated exercise specialists, psycho-oncologists, complementary therapists and more.

[1] https://doi.org/10.1038/s41416-018-0029-6

The Yes to Life Charter for Oncology

Yes to Life has launched the Yes to Life Charter for Oncology[2] which elucidates the cultural shift essential to meaningful change, and the elements required to place patients where they should be, right at the heart of everything that NHS clinicians, managers and patient advocates do. We should support individuals to promote wellbeing and to be active partners in their own healthcare, offering services that meet the needs and preferences of patients, families and their carers.

Although these are already fundamental principles of the NHS, we are currently failing to deliver, with patients instead saying, for example:

"Not once have I been asked how I'm feeling about my diagnosis or if I need any emotional/psychological support"

"I was detailing the wide range of approaches I am employing to beat my stage 4 colorectal cancer: off label drugs, diet, exercise, stress reduction, supplements etc. My comments were mainly greeted with smirks and shrugs, before spitefully (I felt) telling me that my condition was 'incurable'"

"I have found the oncologist just tells you what the next treatment is they will offer. No discussion, no questions really answered. It's totally shocking for a 43 year old man to be so let down by (apparently) the second best lung cancer unit in the country. Maybe we should have gone to the the first... but I have heard that isn't any better"

A solution for all

As other international examples amply demonstrate, integration – supported by the cultural changes outlined in the Charter – is not an additional burden to be placed on already over-stretched healthcare workers, but a solution that, through supporting patients in taking as much control of their own care as is possible, simultaneously provides a direct route to re-engaging staff talent and passion and to improving outcomes and satisfaction. Furthermore, engaging clinicians in the production of publicly available 'real-world' data[3] and putting them at the heart of the development of better outcomes for their patients would inspire a new generation to engage in a highly rewarding pursuit.

We should be aspiring to provide exceptional cancer care in UK, based on listening and understanding the needs of people, and addressing those needs in an individualised way, whilst simultaneously gathering consistent and high-quality real-world data about what works and what doesn't, and adjusting practices accordingly.

It is time we elevate the patient and clinician voices to transform cancer care through integration, bringing patients and clinicians together with commissioners and policy makers to design, adopt and scale Integrative Cancer care pathways in the UK.

Appended: The Yes to Life Charter for Oncology

[2] https://yestolife.org.uk/wp-content/uploads/2024/11/The-Yes-to-Life-Charter-for-Oncology-v4.2.pdf
[3] More on this topic within Q3 responses

Q2. What does your organisation see as the biggest challenges and enablers to move more care from hospitals to communities?

Culture

As detailed in the answer to Q1, that the greatest challenge to making any meaningful change to our NHS service delivery, is the existing culture. This is completely out of step with both developments in public health and attitudes in society and is not an issue the NHS is capable of resolving internally. Meaningful engagement with 'customers' and with third-party organisations, underpinned by a clear recognition of the lack of, and need for, the necessary skills in health promotion, prevention, person-centred care and patient empowerment, is essential for progress.

Locus of care

Currently the locus of cancer care is the oncology unit, which as previously detailed, has no knowledge or skills regarding the lifestyle factors driving almost half of cancers. At least half of Cancer patients in the UK adopt some form of lifestyle or complementary approaches[4] independently, but far from being encouraged in taking steps towards self-management of symptoms and side-effects, the current climate of oncology is such that patients are generally too afraid to inform their oncologist or surgeon, due to fear of judgement.

In summary, patients are largely unsupported during and after their cancer treatment. To remedy this situation, care needs to be extended upstream, as set out in the government's agenda, to include GPs, pharmacies, health centres, and a broad range of complementary and lifestyle services not currently acknowledged as a requirement of good, holistic care.

Education

All of this will have little impact without the 'enabler' of clinician education. The current culture of oncology is one which states that 'We do all the protocol-based treatments - nothing else is important.' This is scientifically inaccurate and even positively negligent when you consider that an exercise programme can be beneficial to the experience and outcome of practically every Cancer treatment programme, and yet in the UK patients very rarely receive this information from their clinician. The clinician is in a powerful position at a highly 'teachable' moment in someone's life to encourage – or discourage – healthy lifestyle choices, so to be routinely telling people it doesn't matter what they eat, given what we know about ultra-processed foods, for example, is highly damaging.

[4] Estimates of usage vary considerably but are clearly substantial. Many studies are quite old. This one shows nearly 50% usage in 2010, since when awareness of integrative medicine has gone up - https://ore.exeter.ac.uk/repository/bitstream/handle/10871/16768/J%20Intgr%20Oncol%202012%20-%20Posadzki.pdf. This more recent US study found 66% of respondents used vitamin supplements - https://pmc.ncbi.nlm.nih.gov/articles/PMC6092049/

Clinicians don't need to be experts in lifestyle medicine, but they do need to know the facts when it comes to its potential, and how patients can get lifestyle support. Also, appropriate pathways for lifestyle support are required, whether in primary, community or secondary care.

Forward investment

To switch from a firefighting approach to health to one of prevention and health promotion will require courageous and far-sighted investment in order to reap the multiple benefits of a healthier population. And although some rewards will be within relatively easy reach, many may be more than a decade in the making. The issues we face today have taken many decades to reach this crisis point, so solutions will also take time. But to transform the current downward spiral into an improving prospect would, in itself, be a huge achievement that will inspire hearts and minds and deliver benefit to society in multiple ways.

'Enabler' resources

Organisations such as the British Society for Integrative Oncology[5] and Yes to Life[6] are huge advocates of prevention, healthy living and living well with Cancer, incorporating supportive oncology approaches to conventional care. They have spent years educating professionals and empowering patients to take control of their health and have achieved a shift in care in some places in the UK. These efforts need to be supported and enhanced through the new government prevention and 'left-shift' agenda.

[4] bsio.org.uk
[5] yestolife.org.uk

Q3. What does your organisation see as the biggest challenges and enablers to making better use of technology in health and care?

Healthcare information

We need a single simple and safe digital solution for easy access to peer-reviewed healthcare information for patients and the public. This should be the prime focus of technology developments, and be given priority over internal systems. This could be the NHS App if designed well for that purpose, or some other solution that is co-designed by patients and clinicians. This solution should give access to information about healthcare services wherever people live, it should have information available in all languages and should be accessible for people with learning difficulties, hearing and visual impairment.

Furthermore, in addition to their own health data, it should supply patients with 'real-world' study data as detailed below, to support decision making.

Personal health data

The personal health data held by the NHS has the potential to provide one of the world's largest resources of 'what really works'. Working outside the profit agenda or any of the other confounding factors that have hindered progress and diminished trust in healthcare, evaluation of 'real-world' data holds immense promise as a means to improve care and re-engage clinicians. Rather than 'endlessly repeating a failed experiment' as Lord Saatchi eloquently described treatment for his wife's cancer type, clinicians could be at the heart of discovering more effective treatments for their patients – a truly inspiring and rewarding mission.

To make this possible, a watertight pledge needs to be made to patients that – if they give their permission – their data will only be used in research by the NHS and never, under any circumstances, passed to any third party or used for any commercial purposes whatsoever. This would begin to re-establish a baseline of trust between clinicians and patients, between the NHS and the public, that all parties are working with a single aim: to improve the treatment of Cancer – a truly patient-centred initiative. This in turn would have the effect of establishing the NHS system as the most trustworthy source of up-to-date health information.

We as an organisation would support the co-design of such a digital tool that can be scaled across UK and beyond.

Q4. What does your organisation see as the biggest challenges and enablers to spotting illnesses earlier and tackling the causes of ill health?

The answers to this overlap with those given to Q2, in terms of the need for far-sighted investment, and the cultural change required to move from the familiar territory of firefighting to the little understood realms of prevention and health promotion.

Inclusion not reinvention

This move is unlikely to be achieved without a clear recognition of the lack of skills and knowledge within the NHS and of those that are quite well developed outside. Integrative Cancer care is, at its heart, person-centred care, a model of care the NHS has completely failed to deliver. There is an entire service sector of complementary and lifestyle practitioners who have been practicing person-centred care for decades and working to discover and remedy root causes rather than manage symptoms. And despite having a free health service, patients are prepared to pay for these services, simply because it's what they want and it works for them.

Collaborate

The most direct 'enabler' to expediting improvements in prevention and early diagnosis is collaboration with charities, commissioners, policy makers, Integrated Care Systems and educational institutions, including Royal Colleges, in recognising and integrating lifestyle and preventive medicine into all specialties, including Cancer.
Bringing charities closer to healthcare and investing in the work they do will support 'left-shift'. This is a cost-effective model of care which will improve population health and address inequalities in access to health and lifestyle advice. This is a model of care which will bring value to other schemes such as patient-initiated follow-up programmes, and self-management closer to homes as opposed to within expensive institutions.

Training and recognition

We have an immediate opportunity to recognise 'Preventive and Lifestyle Medicine' as a specialty supported by its own Royal College, and to integrate trained professionals of all disciplines in primary, community, secondary care.

These significant changes can be delivered in 2 years' time if we start today.

Q5 Please use this box to share specific policy ideas for change. Please include how you would prioritise these and what timeframe you would expect to see this delivered in, for example:

The previous government left Cancer care out of its 10-year plan altogether. Given that the scale of current cancer statistics dwarf the effects of Covid 19, for example, this is completely misjudged. By incremental but accelerating steps we are becoming inured to the catastrophic and untenable situation of half the population receiving a diagnosis. It is time that we challenge and change the failed model of Cancer care.

This can only be achieved if we elevate the patient and clinician voices to transform Cancer care through integration, bringing patients and clinicians together with commissioners and policy makers to design, adopt and scale a much broader model of Integrative Cancer care pathways in the UK.

If we start laying the foundations now, the UK will be able to scale this preventive model of care in 2 years' time and we will see year-on-year improvements in patient outcomes and productivity after that. We will use real-world patient data and digital systems to measure, report and publish on those outcomes.

We are inviting you to a conversation about transforming cancer care. We, and our senior team would welcome an initial meeting as soon as possible to discuss our recommendations.

Contact

CELEBRATING 20 YEARS

Registered charity no: 1112812

71-75 Shelton Street
Covent Garden
London WC2H 9JQ
0203 222 0587

office@yestolife.org.uk

https://yestolife.org.uk/