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COMMISSIONING PERSON CENTRED CARE FOR PEOPLE AFFECTED BY CANCER

INTRODUCTION

Cancer survival is at its highest ever, with significant improvements made over the last 15 years. The number of people living with cancer in the UK has risen by 400,000 in the last five years - taking the total number of people living with cancer in the UK to 2.5 million. More than half of people receiving a cancer diagnosis will now live ten years or more. This progress has been driven by improvements in our knowledge of how to treat and control cancer, combined with the commitment of NHS staff to deliver transformative care. We need to make sure that we don't just help more people to live following a cancer diagnosis, but to live well.

Achieving World-class Cancer Outcomes, A Strategy for England 2015-2020, emphasises the importance of taking a whole person, whole pathway approach to the commissioning and provision of cancer services, and highlights the need to improve quality of life for people living with and beyond cancer as a key component of that. This was reiterated by the Secretary of State in September 2015 in his statement of support for the new strategy, in which he committed to ensuring that every cancer patient receives the interventions known as the 'Recovery Package'.

PURPOSE OF THIS DOCUMENT

This guidance is intended to support commissioners and strategic clinical networks to ensure every person affected by cancer will have access to the Recovery Package and *stratified follow-up pathways by 2020, as set out in the cancer strategy. It describes the actions you will need to take to deliver this including checklists for developing service specifications, practical examples and templates to use and adapt locally.

When developing and implementing these interventions, commissioners should also take into account the duties placed on them under the Equality Act 2010 and with regard to reducing health inequalities, duties under the Health and Social Care Act 2012. Service design and communications should be appropriate and accessible to meet the needs of diverse communities. Guidance for NHS commissioners on Equality and Health Inequalities Legal Duties is also available.

* Specifically breast, colorectal and prostate

CANCER COMMISSIONING

The responsibility for commissioning services is shared across 3 different organisations.

NHS England	Clinical Commissioning Groups	Public Health England
NHS England commissions specialist cancer services for adults including specified rare cancers, specified complex surgery or interventions for more common cancers, chemotherapy and radiotherapy. It also commissions all cancer services for children and young people including radiotherapy services*. NHS England also commissions primary care contracting and cancer screening programmes.	CCGs commission services for patients with common cancers, GP referral, diagnostics, follow up and surveillance, rehabilitation and survivorship and palliative care/end of life care. CCGs also have a duty to support quality improvement in primary care.	Public Health teams in Local Authorities are responsible for health improvement for their populations and health promotion initiatives. This includes raising awareness of cancer symptoms, behavioural and lifestyle campaigns to prevent cancer and general health and wellbeing advice and initiatives.

^{*} Manual for prescribed specialised services, January 2014

THE RECOVERY PACKAGE

The Recovery Package is a set of essential interventions designed to deliver a person centred approach to care for people affected by cancer. This includes:

- Holistic Needs Assessment (HNA) and care planning
- Treatment Summary (TS)
- Health and wellbeing events
- Cancer care review (CCR)

HOLISTIC NEEDS ASSESSMENT (HNA) AND CARE PLANNING

Everyone with cancer should be offered an HNA and care plan. Effective assessment and care planning can lead to early interventions, diagnosis of consequences of treatment, improved communication and better equity of care.

The HNA and care plan ensure that people's physical, emotional and social needs are met in a timely and appropriate way, and that resources are targeted to those who need them most. It should take place around diagnosis, at end of treatment, whenever the patient's needs change or at any other time at the patient's request. For details of what should be included in a service specification and for examples see appendix 1.

TREATMENT SUMMARY (TS)

Developed to support improved communication between cancer services and primary care, the TS is produced by secondary cancer care professionals at the end of primary treatment (the end of first treatment or treatments given) and sent to the patient's GP and other primary care professionals to inform them of any actions they need to take and who to contact with any questions or concerns. The patient also receives a copy to improve understanding of their condition and to provide a summary to share with other professionals.

Treatment Summaries may also be used at other points in the journey, for example following treatment for recurrence or referral from secondary care to palliative care. It is used to inform the GP cancer care review, which is also part of the Recovery Package. A copy of the TS in the case notes is also useful for medical staff if the patient is admitted in an emergency after primary treatment is complete. For further information and example templates see appendix 2.

HEALTH AND WELLBEING EVENTS

Health and wellbeing events provide an opportunity to inform and educate patients about the clinical and holistic aspects and ongoing management of their health. They also serve to impart information about local facilities, supportive care and opportunities that are available to individuals and their families.

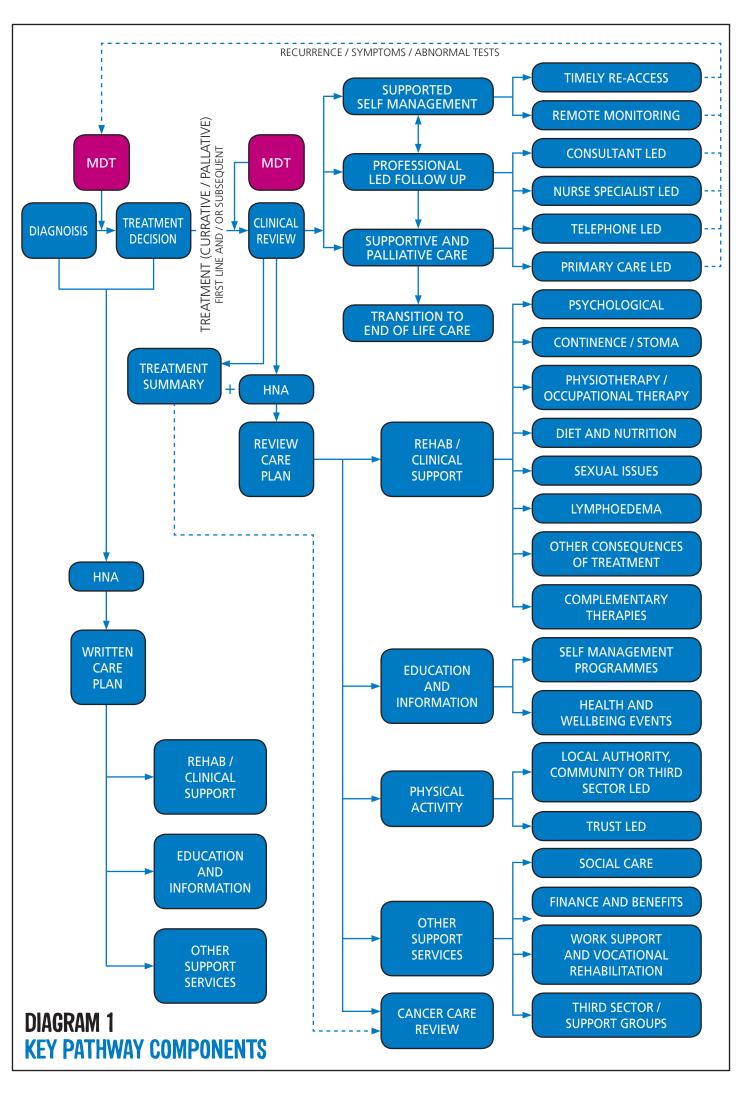
Every individual with cancer should be offered the opportunity to attend a health and wellbeing event at the end of treatment to support them to self-manage their condition. For details of what should be included in a service specification and for examples see appendix 3.

CANCER CARE REVIEW (CCR)

Informed by the Treatment Summary, the cancer care review is completed by a GP or practice nurse in order to discuss the person's needs. It is carried out within six months of a cancer diagnosis and covers post-treatment support, financial impact of cancer, patient awareness of prescription exemptions, possible late effects of cancer and cancer treatment and information needs to enable self-management. Some commissioners in England have local incentive schemes to improve quality, timing and/or frequency of the CCR. The cancer care review is also eligible for Quality Outcomes Framework (QOF) points.

THE WHOLE PERSON, WHOLE PATHWAY APPROACH

The pathway below (Diagram 1) identifies the key components that need to be considered in commissioning and delivering a whole pathway, person centred care approach to people affected by cancer. The interventions should be considered as an integral part of any commissioned pathway across primary, secondary and tertiary care.



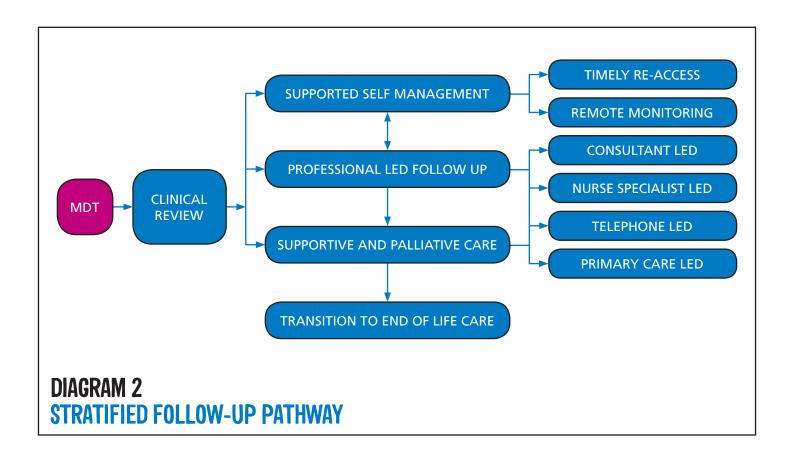
STRATIFIED PATHWAYS OF CARE

Stratified follow-up pathways comprise needs assessment, support for patients to self-manage, remote monitoring and re-entry pathways. This can offer a more effective approach to after-care than traditional medical models of follow-up. More tailored care in this phase has the potential to reduce costs through reducing recurrences, better managing side-effects, improving patient satisfaction and supporting people to live well. All pathways are suitable for stratification; however the National Cancer Strategy (Achieving World-class Cancer Outcomes, A Strategy for England 2015-2020) suggests a primary focus on breast, colorectal and prostate.

In general, individuals deemed at low risk of recurrence and late effects (physical and psychosocial), should be encouraged towards supported self-management, those at medium risk may receive planned coordinated care and those at high risk should receive complex care from specialist services. A system must be developed for rapid re-entry to the specialist cancer service as required.

Further information and examples can be found in appendix 4.

Diagram 2: Stratified follow-up pathway, explains the principle of stratified follow up. This must be considered in the context of the entire pathway (see diagram 1).



WIDER CONSIDERATIONS

To be effective, the Recovery Package and Stratified follow-up pathways must be linked to the commissioning and provision of services required to meet the needs identified, for example:

- Managing the consequences of treatment all patients should be given information and advice on the likelihood and management of potential consequences of treatment or late effects. This includes the wide range of physical and psychosocial changes that reduce independent function or quality of life after cancer and its treatment.
- Rehabilitation services access to adequate and appropriate rehabilitation services is essential
 in order that people living with and beyond cancer achieve optimum function and quality
 of life. All patients must have access to appropriately skilled allied health professionals
 (including occupational therapists, physiotherapists, speech and language therapists, dietitians,
 psychologists and therapeutic radiographers) to support their individual needs throughout
 the whole cancer pathway, where appropriate. For further information on commissioning
 rehabilitation service see Commissioning Guidance for Rehabilitation.

Many of the interventions needed for people affected by cancer are the same as those living with other long term conditions. Commissioners should take this into account by commissioning interventions required by the individual rather than dealing with the cancer in isolation. The commissioning and provision of services to support people affected by cancer may or may not need to be cancer specific but does need to follow the principles of person centred care as laid out in the NHS England Long Term Conditions Framework. For more information, resources and examples see appendix 5.

For commissioners, it is important that all these interventions are included in strategies, commissioning intentions and contracts and discussed with providers. Selections of exemplars from across England are included in appendix 6.

Commissioners should also use the full range of financial and non-financial levers and incentives available to them in order to promote person centred care for people affected by cancer. See appendix 7 for further details.

APPENDICES

APPENDIX 1: HOLISTIC NEEDS ASSESSMENT SERVICE SPECIFICATION AND EXAMPLES

An HNA may require input from a range of doctors, nurses and allied health professionals (e.g. dietitians, physiotherapists, occupational therapists, and speech and language therapists) to improve a person's management and care. This creates a shared understanding between patient and healthcare professionals about what to expect during recovery, and identifies any needs to be addressed.

A service specification for an HNA should include the following:

- Physical concerns
 - Tired / exhausted or fatigued, pain, wound care after surgery, memory or concentration, sexuality.
- Practical concerns

Emotional concerns

- Caring responsibilities, work and education, money or housing, insurance and travel.
- Family / relationship concerns
- Partner, children, relatives, friends, other.
- Loneliness or isolation, sadness or depression, spiritual or religious concerns.
- Lifestyle, work or information needs Support groups, exercise and activity, diet, smoking, alcohol or drugs, sun protection, work support, hobbies.

A Care Plan should be developed as part of this process. This enables appropriate interventions, including support and information, and signposting or referral to other services if required. The process prevents concerns from escalating and supports self-management.

THE FOLLOWING EXAMPLES OF HNAS CAN BE USED AND ADAPTED LOCALLY:

- The Integrated Cancer Services in London have developed a London-wide Holistic Example 1 Needs Assessment template (London Cancer version).
- Macmillan Cancer Support has developed an electronic HNA (eHNA). This allows the Example 2 person affected by cancer to complete the HNA questionnaire on a touch screen tablet. The information is then sent to the clinician through a secure website to begin the process of care and support planning.

APPENDIX 2: TREATMENT SUMMARY INFORMATION AND EXAMPLE TEMPLATES

The TS provides important information for GPs, including possible treatment toxicities, information about side effects and/or consequences of treatment, signs and symptoms of a recurrence, whether they are at risk of developing other conditions such as cardiac disease, osteoporosis and diabetes and any actions for the GP. The form also includes the READ codes for the diagnosis and treatment so that the GP can update their patient database.

Thoroughly tested and positively evaluated by both GPs and oncology clinicians, the TS is now available electronically on the two main cancer information systems: Somerset Cancer Register and InfoFlex Cancer Information Management System.

THE FOLLOWING TEMPLATE EXAMPLES OF TREATMENT SUMMARIES CAN BE USED AND ADAPTED LOCALLY

- **Example 1** Macmillan Cancer Support has developed a Treatment Summary Template and Guidance (2015) describing its use from both a secondary and primary care perspective.
- **Example 2** A London-wide Treatment Summary template has been developed by the Integrated Cancer Services in London. (London Cancer Alliance Version).

APPENDIX 3:

HEALTH AND WELLBEING EVENT SERVICE SPECIFICATION AND EXAMPLES:

A HEALTH AND WELLBEING EVENT SHOULD INCLUDE:

Expert advice on health promotion

To minimise risk of recurrence and support healthy living particularly physical activity, nutrition and healthy weight management, smoking cessation. To include information/support to effect behavioural change.

 Support to ensure that individuals have the confidence and skills to manage their condition themselves

For example referral onward to rehabilitation and psychological support services as appropriate and signposting to local support groups, voluntary sector organisations or buddying services.

- **Information about complementary therapies**How these therapies may help to facilitate wellbeing.
- Advice on adjusting to life after treatment Addressing fears of cancer recurrence.
- Information on signs and symptoms of recurrence and potential consequences of treatment All events should clearly convey and reinforce the methods to activate fast-track access back into the system if there are any concerns regarding new symptoms or recurrent disease.
- Information and access to financial and benefits advice
- Specific issues relevant to the individual's type of cancer

 For example: communication difficulties, dysphagia, colostomy care, prosthetic care, early detection and management of lymphoedema, body image and sexual functioning.
- Work support / vocational rehabilitation
 Access to services for patients including work support and information that patients and carers can share with their employers.
- Management of symptoms
 For example fatigue or physical discomfort.

THE FOLLOWING EXAMPLES OF HEALTH AND WELLBEING EVENTS CAN BE USED AND ADAPTED LOCALLY:

- **Example 1** London Cancer (LC) has developed information and guidance on the development and implementation of health and wellbeing events in order to embed them within cancer pathways: Health and Wellbeing Events Specification.
- Ashford and St. Peter's Hospitals NHS Foundation Trust (ASPH) held their first health and wellbeing event in February 2015. The programme consisted of a range of expert speakers from clinicians and psychologist to dietitians as well as presentations on more practical issues such as seeking financial benefits, carers' support, medical coaching and advice on physical activity for cancer patients. Exhibition stands supported by 14 cancer charities were included to ensure patients and their families and carers are provided and supported with additional information and guidance. A video was produced showing highlights of the day.
- **Example 3** Brighton and Hove CCG has commissioned Albion in the Community to run Brighter Outlook a free, personalised physical activity programme for people living with and beyond cancer in Brighton and Hove.

APPENDIX 4: STRATIFIED FOLLOW-UP PATHWAYS INFORMATION AND EXAMPLES

NHS Improvement (2013) produced the document Stratified Pathways of Care: How to Guide. This legacy document still provides useful information and resources for the implementation of Stratified Pathways of Care.

EXAMPLES OF STRATIFIED PATHWAYS OF CARE TO BE USED OR ADAPTED LOCALLY

- Example 1 Broomfield Hospital, Mid Essex NHS Trust has provided stratified follow up for colorectal cancer patients for almost 10 years, saving approximately 600 outpatient appointments per year. With 200 new cases a year, about half the patients are suitable for stratified follow up and they have received 85 per cent positive feedback. The data is captured on Infoflex. A journal paper describing this work has been published in Colorectal Disease 'Remote surveillance after colorectal cancer surgery: an effective alternative to standard clinic based follow-up'.
- Example 2 Transforming Cancer Services Team for London have developed a primary care stratified follow-up pathway for prostate cancer (The Croydon Model). It compromises a number of elements: monitoring of the Prostate Specific Antigen (PSA) test and symptoms to detect signs of recurrence, detection and management of the consequences of treatment through holistic assessment and care planning, and support to patients to self-manage. They have described the pathway and developed FAO for commissioners.

APPENDIX 5:

ALIGNING WITH LONG TERM CONDITIONS (LTC) AND COMORBIDITIES INFORMATION AND EXAMPLES

More people are surviving cancer and living with co-morbidities. Seven in ten people with cancer have at least one other long-term condition, which equates to 1.8 million people. Some people with cancer have a higher risk of developing certain long term conditions many years after their treatment for cancer for example, diabetes, osteoporosis, and cardiovascular problems as well as a second primary cancer.

Personalised care and support planning is a systematic way of ensuring that individuals living with one or more LTC, their carers, and their health and care professionals work together to achieve what matters most to that individual. It can also lead to the most appropriate use of limited healthcare resources.

People who are engaged in their health and care are more likely to receive care and treatment that is appropriate to them; to take up appropriate prevention services (such as regular screening), and to adopt healthier behaviours. By sustaining successful self-management, and by anticipating and making explicit provision for possible crises and emergencies, personalised care and support planning may also help to reduce the use of urgent and emergency care.

Working in partnership to commission integrated pathways of care reduces barriers imposed by organisational boundaries and allows services to be commissioned according to the needs of the individual.

NHS ENGLAND HAS DEVELOPED COMPLEMENTARY GUIDANCE FOR COMMISSIONERS FOR PERSONALISED CARE AND SUPPORT PLANNING FOR LONG TERM CONDITIONS:

- Personalised care and support planning handbook: The journey to person centred care;
- Guidance on delivering personalised care and support planning: The journey to person-centred care;
- Transforming participation in health and care; and
- Long term conditions improvement programme.

EXAMPLES OF INTEGRATED CARE

- **Example 1** The Think Local Act Personal (TLAP) online tool has been developed to inform and guide leaders, commissioners, planners, clinicians and practitioners through designing and delivering personalised care and support planning for people with a variety of health and social care needs. It is done through a series of case study scenarios, developed with people in the field, clinicians, social care managers, voluntary sector partners and people with lived experience of care.
- Example 2 The CQUIN produced by Mid Nottinghamshire CCGs was developed as an enabler for wider system change that aligns with the LTC agenda. The focus is on information sharing across secondary and primary care, and is part of a wider approach to development of community and primary care services; underpinned by a person centred approach to care seen in their Better Together Transformation Programme.
- North West London (NWL) 'Whole Systems Integrated Care' brings together health and social care providers, commissioners, the third sector, and service users to co-produce and implement new models of care. Through 18 months of collaborative design work the partners produced a joint 'Integration Toolkit', which local areas have used to develop their proposals in more detail. Nine 'Early Adopters' are now starting to test their models in practice, for subsequent wider roll out. Tools used include holistic needs assessment, innovative data sharing (supporting both care delivery and development of new capitated payment models), stratified care pathways, and proactive case management. In the coming months, partners across NWL will start to form shadow 'Accountable Care Partnerships' to take the work to the next phase. Further details can be found on their website.

APPENDIX 6:

COMMISSIONING IN LOCAL STRATEGIES, COMMISSIONING INTENTIONS AND CONTRACTS - EXAMPLES

LOCAL STRATEGIES

- Example 1 The Wessex Clinical Commissioning Groups (CCGs) tasked the Strategic Clinical Network with describing a strategic vision for cancer services over the next five years. This includes: 'Within 5 years all Wessex patients with a new cancer diagnosis will be offered a holistic needs assessment, a primary care cancer review and a detailed treatment summary, as a consequence of the implementation of the Recovery Package'.
- **Example 2** Mid Nottinghamshire CCGs have developed a strategy that includes their commissioning intentions for delivering adult cancer services. It describes the growing need to review and redesign cancer services across Mid Nottinghamshire and the opportunities to deliver structural and cultural change as part of a wider health economy cancer service redesign programme.

COMMISSIONING INTENTIONS

- **Example 1** Transforming Cancer Services Team (TCST) for London has developed commissioning intentions that include:
 - Recovery package;
 - Pathways for Consequences of Treatment including Lymphoedema, bladder, bowel, sexual dysfunction, fertility, hormonal treatment and psychological support; and
 - Stratified pathways for breast, colorectal and prostate (some commissioners are choosing a primary care led prostate follow up pathway).
- **Example 2** Thanet CCGs have a focus on commissioning intentions in the light of better integrating care. This includes primary care working with community nursing, and secondary care clinicians supporting patients in the community. The CCG is supportive of integrating cancer into these services.

CONTRACTS

This guidance document should act as a checklist for developing service specifications.

Example 1 A service specification for self-supported management of colorectal cancer has been developed by Sheffield CCG. It includes risk stratification within secondary care prior to discharge. Contact details can be found on their website.

APPENDIX 7: INFORMATION AND EXAMPLES OF FINANCIAL AND NON-FINANCIAL LEVERS AND INCENTIVES

FINANCIAL:

- Using the contract to manage quality (NHS England Standard Contract 15/16) to ensure that patients have access to a range of high-quality services is the core function of NHS commissioning. The contract supports this by giving a robust framework through which a commissioner can set clear standards for a provider and hold it to account for the quality of care it (and any sub-contractors) delivers. The contract provides processes through which commissioners can intervene to ensure that high-quality care is delivered by requiring regular submission of monitoring information, agreeing Service Development and Improvement Plans, offering incentive schemes to improve quality, requiring Remedial Action Plans to address service deficiencies, applying financial sanctions for failure to achieve national standards, and ultimately by suspending services temporarily or terminating them permanently;
- Quality premium payment to CCGs for improvement in quality of services commissioned;
- Commissioning for Quality and Innovation (CQUIN) payment to incentivise quality and innovation improvements over and above the baseline requirements set out in the NHS standard contract;
- Quality Outcome Framework (QOF) payment mechanism for GPs for quality care against set of indicators for example the cancer care review;
- Best practice tariffs (BPT) to incentivise care with specific high quality cost effective treatments; and
- National and local enhanced service schemes.

NON-FINANCIAL:

- CCG outcomes indicator set to give clear comparative information about the quality of health services commissioned by CCGs and the associated health outcomes; and
- Commissioning for value / pathways on a page support CCGs to understand where they are outliers and focus improvements for best effect. Also see Rightcare Commissioning for Value.
- Example 1 Mid Nottinghamshire CCGs have developed a Cancer Care and Pathways CQUIN. The indicator includes: 'Every patient with a cancer diagnosis will have at a minimum, a holistic needs assessment and care plan around the time of diagnosis and on completion of treatment, and that a treatment summary record will be completed. These key documents will be shared with the patient's GP.'
- **Example 2** West Midlands SCN has developed CQUINs for both Health and Wellbeing events and Treatment Summaries. Contact details can be found on their website.

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EQUALITY AND HEALTH INEQUALITIES STATEMENT

Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have:

- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.