Made in London

New Approaches to Self-Care for Young Adults

Project Report

www.londonsenate.nhs.uk/supporting-young-adults-to-self-care

NHS

London Clinical Senate

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An Overview of The London Clinical Senate

The London Clinical Senate supports development of the capital's health service and improvements in quality and outcomes by providing independent advice to commissioners, and other bodies, supporting them to make the best decisions about health care for their populations.

The Clinical Senate is a multi-professional body, bringing together a wide range of health and care professionals with patients and drawing on their expertise, influence and leadership in the work they do.

The London Clinical Senate comprises a **Senate Council** and **Senate Forum**.

The **Senate Council** provides overall leadership and oversees the provision of advice. It has an independent chair, Dr Jane Collins, Chief Executive of Marie Curie, and twenty-four other members.

The **Clinical Senate Forum** is a larger group with a membership of around 350. It provides a vehicle for clinicians and patients to debate ideas and build consensus on issues of strategic importance. It helps clinical leaders keep up to date with developments, builds links across the clinical community and enables sharing of best practice. The Council draws on the Forum's views and expertise in developing advice on specific issues.

Further information including membership of the Senate Council and Forum, can be found at:
www.londonsenate.nhs.uk.
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PART I / PROJECT OVERVIEW

The NHS Five Year Forward View:

"Long term conditions are now a central task of the NHS; caring for these needs requires a partnership with patients over the longer term rather providing single, unconnected 'episodes' of care."

MADE in LONDON: New Approaches to Self-Care for Young Adults

"You can only take responsibility and be in control of your health if there are services to support you."

"You only see the GP when there is a problem. There is no way of knowing how I am doing and if I am on the right track [the rest of the time]."

Young Adults (Feedback from Engagement Workshops)

Made in London:

New Approaches to Self-Care for Young Adults

// The ***Made in London (MiL)*** project was designed and implemented with the aim of creating a framework for embedding self-care in the commissioning of services for young adults in London.

Initiated by the Patient and Public Voice Group (PPV), part of the London Clinical Senate, it builds on recommendations set forth in the *NHS England Five Year Forward View (2014)* that highlighted the importance of supporting people to manage their own health and giving patients greater control of their care.

The Senate identified young adults, those between 16 and 30, as a group that was not only underserved but could also, in itself, be an invaluable resource in generating and driving a sustainable programme of work.

The Senate agreed that it could add greatest value in promoting self-care for young adults by identifying standards of good practice and building an extensive evidence base; engaging young adults in identifying barriers as well as co-production of services; developing a self-care framework or methodology that could be scaleable and transferable across London; and, finally, highlighting recommendations that can be adopted and applied at a Clinical Commissioning Group (CCG) and Community level to have the greatest positive impact on self-care support.

This report provides an overview of the project, and presents both the process undertaken, and the outcomes generated. The content is organised into three parts as summarised below:

Part I / Project Overview

Part I provides a broad overview of the project, including how and why it was initiated, project goals, approach undertaken, and scope of work.

Part II / Building an Evidence Base

Part II is a synthesis of all the evidence collected during the project. It is broken into three chapters which also reflect the progression through the project.

Chapter 2: Evidence Review presents the findings from an extensive review of the policy and organisational context around self-care support.

Chapter 3: Call for Evidence provides a summary from the first level of engagement that invited different organisations across London to share their experiences of self-care programmes in practice.

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Chapter 4: Engagement Workshops brings together the feedback from a series of engagement workshops co-hosted with young adults across London.

Chapter 5: Outcomes summarises the main outcomes from the Call for Evidence, Engagement Workshops, and the Evidence Review. It highlights key issues and themes that emerged and provides context for the recommendations in the following chapter.

Part III / Recommendations

Building on the combined feedback from the previous phase, Part III highlights priority areas for commissioners and presents a series of recommendations for the design and development of a self-care framework.

Chapter 6: Recommendations presents '10 Key Points for Commissioners' in planning for self-care support, and introduces the 'Self-Care Wheel', an evaluative tool developed during the project, which can be used to assess the potential effectiveness of any given initiative or programme in addressing self-care.

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PART I

PROJECT OVERVIEW

CHAPTER 1 / MADE IN LONDON

1.1 Context

1.2 Project Goals

1.3 Approach

1.4 Scope of Work

1.1 Context

The theme of the Clinical Senate Forum in April 2014 was Supporting Londoners to live well. The Senate had identified self-care as a major priority for the health system in London. It also emerged as an important issue through the work of the London Health Commission.

Self-care is about individuals taking responsibility for their own health and well-being and a key question is "what can the NHS do to support people to self-care?"

More effective self-care has the potential to improve the health and well-being of Londoners, reduce demand on the NHS and ensure available resources are used more efficiently.

With this in mind the Clinical Senate Forum considered the challenges and opportunities associated with self care and where the Senate could add greatest value.

In June 2014, guided by recommendations from the Senate's Patient and Public Voice Group (PPV), the Senate Council agreed to undertake a programme of work designed to:

1. **Promote self-care, particularly for younger people (where there is felt to be a gap)**
2. **Identify standards of good practice**
3. **Bring together the evidence base**
4. **Consider the potential value of IT and social media**
5. **Consider the education and training needs around self-care**
6. **Maximise the support of self-care in the work place**

A Programme Board was established to oversee this programme of work which ran from the autumn of 2014 through to the autumn of 2015. This has been co-chaired by Alexander Silverstein and Council member Professor Jacqueline Dunkley-Bent.

It is hoped early outcomes will inform commissioning for the period 2015/16. A lot of relevant work is taking place across London, though this can be difficult to identify and evaluation appears limited. The Clinical Senate is keen to take a collaborative approach and involve different stakeholders in this work to build on knowledge and expertise that exists.

1.2 Project Goals

The Made in London (MiL) project was initiated by the Patient and Public Voice Group (PPV) with the aim of:

Creating a framework for embedding self-care in the commissioning of services for young adults in London

In this context 'young adults' refers to those between the ages of 16 and 30, and especially:

- Young adults with Long Term Conditions (LTCs), and

- Carers of young adults with LTCs (including young carers).

The proposed goal was to create a framework that would not only highlight priority areas and key recommendations that are needed to support self-care for young adults, but would also define a process, or methodology, that could be both transferrable and scaleable to other similar programmes for use across London.

Furthermore, it was agreed that for the framework to be successful, young adults would have to be at the forefront of the project by being given a platform on which to express their opinions, share concerns, and make recommendations. By engaging them in a process of shared decision-making, they would be able to shape the programme agenda and endorse final recommendations.

While the programme board selected a provisional definition of Self-Care (below) at the start of the project, they agreed that it would be necessary to co-create a final definition with young adults themselves in the process of engagement.

Self-Care Definition

> *"Self-Care includes aspects that relate to health, illness, disability, general outcomes, the performer of self-care, the action of self-care, the relation to the healthcare professionals, and the relation to the healthcare system.*
>
> *Individuals perform self-care by taking responsibility for their own care or care of another. Self-care can be performed independently, or guided or informed by a health professional to promote physical or psychological health."* Godfrey et al (2011)

Recognising that the approach taken to delivering this programme was as essential to its success and as valuable to commissioners as the recommendations

1.3 Approach

— the programme was designed using the following principles:

(i) Collaborative: Bringing young adults/carers, commissioners, and professionals together as equal partners to identify gaps and develop standards for good practice.

(ii) Evidence-based: Develop and promote evidence-based solutions to support self-care for young adults aged between 16-30.

(iii) Asset-based: Develop the capacity of young adults to engage effectively in identifying needs, making recommendations, and in planning/development of services.

(iv) Continuous and iterative: Engaging to build and refine sustainable models for local and pan-London commissioning that reflect the needs and aspirations of young adults.

1.4 Scope of Work

The Made in London project was designed around four key phases, as highlighted in the following diagram (Illustration 1.4_a). These include:

(i) Evidence Review;

(ii) Call for Evidence;

(iii) Engagement Workshops; and,

(iv) Recommendations (Collaborative Review).

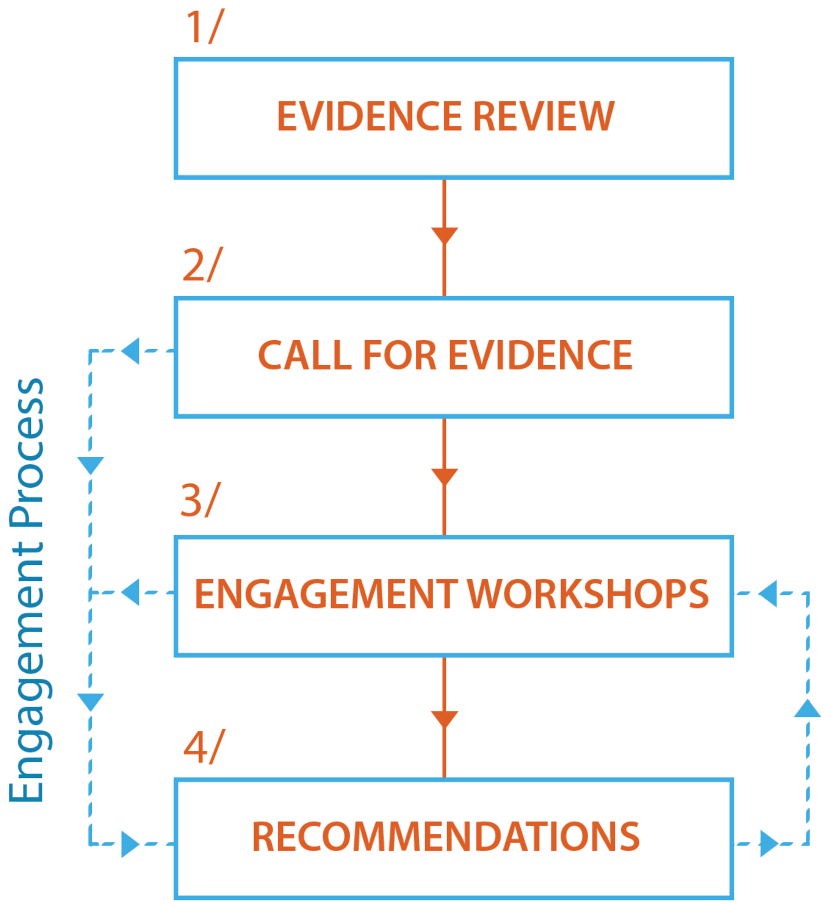
One of the defining characteristics of the project design was its asset-based approach. It was understood at the outset that in order to effectively involve young adults in driving the programme forward, they would need to be provided with the necessary training and skills to allow them to participate in the design and evaluation of services.

Given these different factors, it is anticipated that both the approach used and the findings will be applicable and of interest to the health and care sectors more broadly.

1.4 Scope of Work

Underscored by a process-oriented and collaborative approach (as highlighted above), the project was designed around four main phases as summarised below:

Illustration 1.4a / Scope of Work



1// A review of the existing policy and organisational context around self-care support to identify needs and current best practice in programmes for young adults in general, and those with LTCs in particular. This was seen as an essential starting point for the project and would form the foundation on which all the other project phases would be built.

2// Building on the Evidence Review, the Call for Evidence created a space for service providers and community organisations across London to share their experiences of self-care programmes and highlight best practices. As well as identifiying key issues, it enabled the creation of a draft framework to be used as the basis for wider engagement.

3// Four community based engagement events were held across London in July 2015 to build on earlier recommendations. Local host organisations were commissioned to undertake the outreach and engagement for these events, including identifying young adults to co-facilitate and lead the main workshops.

4// An additional workshop was organised in October 2015 and served as a platform to collaboratively review the draft recommendations. Young adults, partners, and other stakeholders, were invited to participate and share their thoughts/ideas/suggestions on the proposed next steps, and ensure that the recommendations did, indeed, reflect their earlier feedback.

PART II / BUILDING AN EVIDENCE BASE

PART II

BUILDING AN EVIDENCE BASE

CHAPTER 2 / EVIDENCE REVIEW

2.1 Overview

2.2 Strategic Context

2.3 What is Unique about London?
2.4 Mental Wellbeing & Young Adults
2.5 Young Adults & Families' Perspectives

2.6 What Works for Self-Care?
2.7 Building the *House of Care*

2.8 References

2.1 Overview

The NHS Five Year Forward View [20] highlighted the importance of supporting people to manage their own health and giving patients greater control of their care. It states that:

> *"Long term conditions are now a central task of the NHS; caring for these needs requires a partnership with patients over the longer term rather than providing for single, unconnected 'episodes' of care" -- and makes an explicit commitment to -- "do more to support people to manage their own health [by] staying healthy, making informed choices of treatment, managing conditions and avoiding complications.*
>
> *"With the help of voluntary sector partners, we will invest significantly in evidence-based approaches such as group-based education for people with specific conditions and self-management educational courses, as well as encouraging independent peer-to-peer communities to emerge."*

In response to these recommendations, NHS England published guidance to support commissioners and practitioners in planning services for people with long term conditions in January 2015. The Personalised Care for Long Term Conditions [10] guidance recommends that commissioners should:

// **Ensure that commissioning reflects the needs of individuals, and commission appropriate person-centred services** that promote and embed personalised care and support planning;

// **Promote partnership and collaboration in local health populations to implement a whole system approach;**

// **Commission a range of support services** for self-management to supplement traditional services and to **ensure a 'more than medicine' approach.** This could include structured education programmes, community activities and peer support networks;

// Ensure that support is in place to **provide people with timely, appropriate and accessible information** to enable them to make an informed contribution to discussions regarding their condition, care and support;

// **Promote the development of clinical environments that encourage shared decision-making** approaches and ensure support systems are in place to support patients who are less able to embrace this approach;

// **Promote the development of the workforce** to have the skills and competencies to work in this way; and,

// Ensure a robust local measurement system is in place to inform and support improvement.

2.2 Strategic Context

> *'The NHS should be supporting people to be as independent and healthy as possible if they live with a long-term condition such as heart disease, asthma or depression, preventing complications and the need to go into hospital. If they do need to be treated in hospital, the NHS should work with social care and other services to ensure that people are supported to leave hospital and recover in the community.'* [20]

Increasing Demand on Services

Health and social care services are facing a huge challenge as people live longer, increasing the likelihood that they will experience long-term illnesses and/or co-morbidities that require ongoing care [12].

The Department of Health estimates that 15 million adults in Britain may currently be living with one or more long-term condition (LTC), and the number of people with multiple long-term conditions is predicted to rise by a third over the next ten years [13].

Not only are the instances of long-term illness increasing, but the number of people with multiple long-term conditions is rising [10]. For example, the number of people with three or more LTCs is predicted to rise from 1.9 million in 2008 to 2.9 million in 2018 [13].

Current Support Offered by the NHS is Costly

// Department of Health data suggests that patients with LTCs account for 50% of all GP appointments, 64 % of all outpatient appointments, and 70% of all inpatient bed days. A significant proportion of patients with mental health conditions also suffer from mental health problems which exacerbate total health costs by a factor of at least 45% [28].

// The current treatment and care for people with LTCs is estimated to take up around £7 in every £10 of total health and social care expenditure. This means that 30% of the population account for 70% of health and social care spend [7].

// The ageing population and increased prevalence of LTCs have a significant impact on health and social care and may require **£5 billion additional expenditure by 2018** [7].

And Not Fit for Purpose

The current health and social care systems are not sustainable in the face of the projected future increase in co-morbidity and the level of need predicted [1,2,3,4,11].

The current systems are primarily designed for short,

2.2 Strategic Context ... cont'd

episodic (medical) interventions with the healthcare professional in a 'one-up' position. This has led to limited outcomes for patients who can quickly lose the confidence and motivation to self-manage when faced with unresponsive and unsupportive clinicians and services [12].

There is an over-emphasis, in current self-care policy and research in the UK, on providing training to people with LTCs without either providing training to health care professionals to support self-care behaviours or making service improvements to embed self-care within service provision [13].

People living with LTCs are not actively and systematically involved in the design and improvements of the services that they use. Thus there is a 'distance' between service-user's expectation of care and support and the provision of this care and support from health and social care systems [3].

LTCs Adversely Affect Health & Wellbeing

Living with a LTC usually reduces people's quality of life, particularly through having and managing chronic pain. People with co-morbidities can find their ability to live life severely affected by a number of factors:

// Those living with an LTC have an increased prevalence of unemployment. Those with a limiting LTC are half as likely to have a job as those with non-limiting LTC or with no LTC [7].

// There is a strong link between physical LTCs and psychological distress and disorder. For example, compared with the general population, people living with LTCs have triple the reported rate of psychological disorders [7].

// Multi-morbidity, or living with multiple LTCs, is more common amongst deprived populations, and there is some evidence to suggest that multi-morbidity is negatively correlated with service access and use [11].

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2.3 What is Unique about London?

Population Profile of Children and Young Adults

Population: Nearly 1 in 4 people in London are children and young people under 20 years. Over 300 languages are spoken by London pupils. There are wide variations in the proportions of children living in different London boroughs. In Barking and Dagenham almost 1 in 3 (31.8%) of the population is aged under 20 years, whilst in the City of London less than 1 in 8 (11.8%) are aged under 20 years. The numbers of children and young people living in London are estimated to rise by 11% between 2012 and 2020, [21,22].

Socio-economic status: About 3 in 10 children in London live in poverty, 1 in 7 children in London live in poor housing and 1 in 4 children live in overcrowded houses. Of the 15 most overcrowded wards, 13 are in London

Ethnicity: In 2011, 68.2% of school children aged 5-16 years in London were from black and minority ethnic groups compared to 25.6% in England. Brent, the most ethnically diverse borough in the country, has the highest percentage of non-white British pupils in secondary school at 94.5%.

Languages spoken at school: Over 300 languages are spoken by London pupils, and around 40% of them do not have English as their first language. Bengali, Urdu and Somali are the top three languages spoken in London, other than English. English is the predominant language spoken in most of Outer London, whereas languages other than English are most common in Inner London.

Health Profile: Adolescence is a period when significant physical, psychological, and behavioural changes occur and when young people develop many of the habits, behavioural patterns and relationships they will carry into their adult lives, for example:

// Nearly 90% of lifetime smoking and 80% of lifetime alcohol or cannabis use is initiated under 20 in the UK.

// One-third of the total disease burden in adults are associated with conditions or behaviours that began in their youth, including: tobacco use, a lack of physical activity, unprotected sex, or exposure to violence [2]

// All causes of mortality among adolescents is now higher than for other periods of childhood except the newborn period. Injuries are the main cause of adolescent mortality.

2.4 Mental Wellbeing & Young Adults

About 75% of lifetime mental health disorders have their onset before 18 years of age, with the peak onset of most conditions from 8 to 15 years. About 10% of adolescents suffer from a mental health problem at any one time.

Good mental health and resilience is fundamental to physical health, relationships, education, work and to individuals achieving their potential. Mental illness is the largest single source of burden of disease in the UK.

Mental ill health has a significant impact on a range of outcomes. In the case of children and young people, this includes poor educational achievement and a greater risk of suicide and substance misuse, antisocial behaviour, offending and early pregnancy.

Poor mental health in childhood and adolescence is further associated with a broad range of poor health outcomes in adulthood. These include:

// About 75% of lifetime mental health disorders have their onset before 18 years of age, with the peak onset of most conditions being from 8 to 15 years. Estimates show that:

// At least 1 in 10 children aged 5-16 have a clinically significant mental health problem. There are currently 1.1 million people in London between the ages of 5 and 16, so mental ill health affects about 111,000 children aged 5-16 living in London.

// National estimates suggest that 45% of looked after children aged 5-17 years experience a mental health disorder, 37% have clinically significant conduct disorders, 12% have emotional disorders, such as anxiety or depression, and that 7% were are hyperkinetic.

// Young people with mental ill health are more likely to find themselves not in education, employment or training (NEET). Poor mental health is associated with an increased probability of being NEET of 2.7 percentage points for girls and 3.3 percentage points for boys. It is estimated that the lifetime resource cost of being NEET is around £104,000, most of which is due to reduced employment and productivity, and means that future work-lessness of children with mental health problems could lead to substantial output losses.

// At least 1 in 15 people aged 11 to 25 deliberately self harm. In London, this translates to 108,000 young people.

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2.4 Mental Wellbeing & Young Adults ... cont'd

Financial Impact of Mental Illness

The impacts of childhood psychiatric disorders cost London's education system approximately £200 million per year.

A review of economic evaluations of mental illness in childhood and adolescence, such as emotional and behavioural disturbances or antisocial behaviour, found mean costs to UK society to range from £11,030 to £59,130 annually per child. Lifetime costs of child conduct disorder in the UK for each 1-year cohort amount to £5.2 billion. In London, the annual cost of physical and emotional harm due to crimes related to conduct disorder is estimated to be between £0.32 and £0.37 billion.

Parenting interventions for children with conduct disorder cost about £1,200 per child. They have been shown to produce savings of around £8,000 for each child over a 25-year period (14% of the savings are in the NHS, 5% in the education system, and 17% in the criminal justice system). Given that half of lifetime mental illness arises by the age of 14, prevention and promotion interventions during childhood and adolescence are particularly cost-effective, with economic returns of early childhood intervention programmes exceeding cost by an average ratio of 1:6.

2.5 Young Adults & Families' Perspectives

One of the key messages within the report of the children and young people's health outcomes forum was:

> *"Children, young people and their families really struggle to get their voices heard and to be involved in decisions about their own health. This makes it difficult for them to take responsibility for their treatment and care."* [22]

Further reports on what matters to children, young adults and their families in relation to self care [23,24,25,26,27], are highlighted in the following priorities:

// Engaging with young adults and their families from the start.

// All changes must be driven and underpinned by an understanding of the needs and wishes of young adults.

// Young adults must have a say in decisions about their health, and encouraged to take a lead.

// Service Users must be enabled to give their own views about their health needs and the care they receive.

// HCPs must show respect for and recognise the right of patients to be involved in decisions about their health and care.

2.5 Young Adults & Families' Perspectives ... cont'd

In addition, promoting self-care and shared decision-making must include the provisions of:

// Support services including one-to-one support from a named key worker, contactable by text, phone and e-mail, provided effective and flexible services to meet young adult's needs.

// Social events and social media are valued by young adults. **Promoting peer support** using social and residential events was valued greatly, as well as using **social media to improve and enhance communications with and between young adults.**

// Personalised action plans as part of a structured educational discussion.

// Self-care advice that is age-appropriate, that focuses on individual needs and is reinforced by a written personalised action plan.

// Professionals to empower adolescents to manage as much of their condition as they are capable of, while supporting parents to gradually hand over responsibility for management to their child.

// Innovative approaches to self-care advice for young adults, (e.g. web-based, in groups, peer-delivered within schools, in the workplace), as these appear to have more success than more traditional programmes.

// Access to a comprehensive network of care with staff (including GPs) that are trained and competent and feel confident that they are able to provide a high standard of care. Families want to feel confident that they are receiving the best clinical care in accordance with NICE guidance and other quality standards.

// Information and support for families/carers so that they are confident about how to manage their child's condition on a day to day basis.

// Schools and social care settings need the capacity and resources to allow them to manage medical conditions. Where this is the case we would expect to see fewer admissions through A&E.

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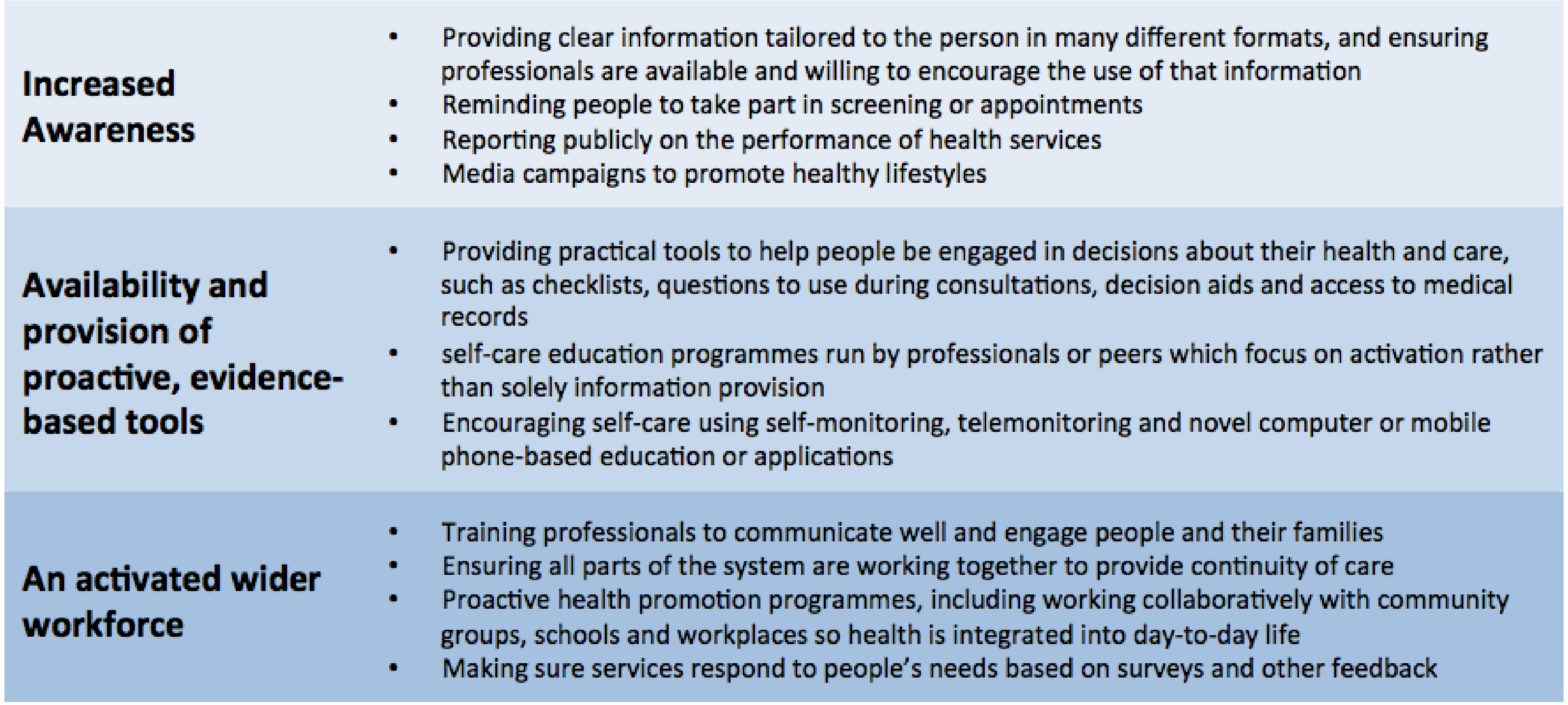
2.6 What Works for Self-Care Support?

Knowledge in this area is developing - evidence about the best strategies to support behavior change and improve management of long-term conditions is currently limited. However, large-scale research reviews and patient and workforce feedback suggests that there are three major components needed for successful self-care [15] --

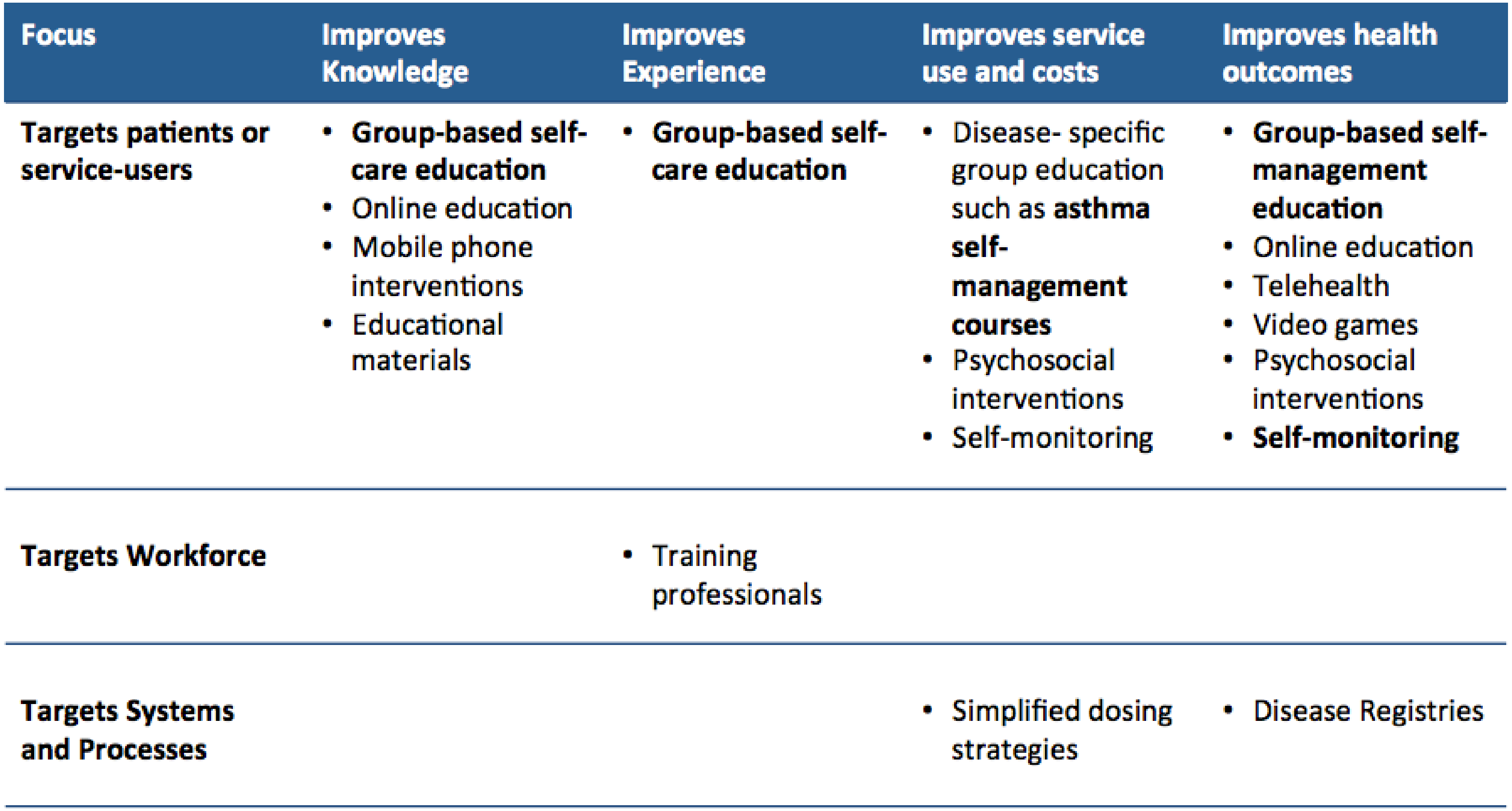


Increased Awareness	• Providing clear information tailored to the person in many different formats, and ensuring professionals are available and willing to encourage the use of that information • Reminding people to take part in screening or appointments • Reporting publicly on the performance of health services • Media campaigns to promote healthy lifestyles
Availability and provision of proactive, evidence-based tools	• Providing practical tools to help people be engaged in decisions about their health and care, such as checklists, questions to use during consultations, decision aids and access to medical records • self-care education programmes run by professionals or peers which focus on activation rather than solely information provision • Encouraging self-care using self-monitoring, telemonitoring and novel computer or mobile phone-based education or applications
An activated wider workforce	• Training professionals to communicate well and engage people and their families • Ensuring all parts of the system are working together to provide continuity of care • Proactive health promotion programmes, including working collaboratively with community groups, schools and workplaces so health is integrated into day-to-day life • Making sure services respond to people's needs based on surveys and other feedback

These 'components' cannot operate in isolation. It is only through improving the way that self-care support is offered, and integrating support services, that sustainable change will be achieved. This means that there needs to be improvements in systems supporting these components to deliver effective change [1, 2, 3].

2.6 What Works for Self-Care Support? ... cont'd

This table provides a summary of the type of interventions with either a patient, workforce or system focus, and are based on a systematic review of 228 studies [15]. Services in bold have the most evidence-support for efficacy.



Focus	Improves Knowledge	Improves Experience	Improves service use and costs	Improves health outcomes
Targets patients or service-users	• **Group-based self-care education** • Online education • Mobile phone interventions • Educational materials	• **Group-based self-care education**	• Disease- specific group education such as **asthma self-management courses** • Psychosocial interventions • Self-monitoring	• **Group-based self-management education** • Online education • Telehealth • Video games • Psychosocial interventions • **Self-monitoring**
Targets Workforce		• Training professionals		
Targets Systems and Processes			• Simplified dosing strategies	• Disease Registries

2.7 Building the House of Care

The need to improve the treatment and management of long-term conditions is the most important challenge facing the NHS. Improving care for people with long-term conditions must involve a shift away from a reactive, disease-focused, fragmented model of care towards one that is more proactive, holistic and preventive, in which people with long-term conditions are encouraged to play a central role in managing their own care.

More than 15 million people have a long-term condition such as hypertension, depression, asthma, diabetes, coronary heart disease, chronic kidney disease, or other health problem or disability for which there is no cure. These people tend to be heavy users of health care resources, accounting for at least 50 per cent of all general practitioner (GP) appointments, 64 per cent of outpatient appointments and 70 per cent of all inpatient bed days (Department of Health 2012). Special analysis of 'Social Care at the End of Life' project data indicates that an estimated 18 per cent of people with long-term conditions are in receipt of state-funded social care (T Georghiou, personal communication 2013).

People with long-term conditions are managing their health on a daily basis, but they may need additional help to develop their confidence in fulfilling their role as a self-manager. This may include support to enhance their ability to manage their tests or medicines, to make changes to their lifestyle or to cope with the emotional and social consequences of living with a long-term condition (Corbin and Strauss 1988).

The call for a more person-centred, better co-ordinated approach to managing care for people with long-term conditions has been embraced by numerous advisory bodies, advocacy groups, governments and international agencies. For instance, National Voices – a coalition of more than 140 UK health and social care charities – developed a first-person narrative to explain what the gold standard of care looks like. This requires making the patient perspective (or that of the service user) the organising principle of integrated care, and can be summarised as follows: *'I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me,'* (National Voices 2013).

While there is now a consensus on the need to transform the model of care for people with long-term conditions, up until now there has been less clarity about the specific changes required. The house of Care metaphor was devised to help those working in primary care adapt the chronic care model to their own situation. It explicitly places the patient at the heart of the delivery system.

The House of Care reinforces the whole-system

2.7 Building the House of Care ... cont'd

approach needed and acts as both a metaphor and an implementation checklist.

As a metaphor, it emphasises the interdependence of each of the components, enabling the new style of clinical consultation. (see Illustration 2.7a) If one 'wall' is weak, the structure is not fit for purpose. This is a collaborative process designed to bring together the perspectives and expertise of both the individual and the professional(s) involved in providing care, offering tailored personal support to develop the confidence and competence needed for effective self-management. The two side walls of the house – engaged, informed patients and health care professionals committed to partnership working – are equally important. Patients may need extra encouragement to participate in a more active way than they are used to, so consideration needs to be given to preparing them for this new role. Staff need to understand this new way of working, value the contribution that each person can bring to their care and develop the skills to support self-management.

[King's Fund Policy Document: Delivering better services for people with long-term conditions. Building the house of care, October 2013]

2.7 Building the House of Care ... cont'd

Illustration 2.7a / House of Care

2.7 Building the House of Care ... cont'd

The Health Foundation's three-tiered approach is based on the 'House of Care" and offers a framework for holistic self-care transformation. The Health Foundation suggest that changes to self-care support services need to happen in parallel – they cannot simply focus on one area of improvement whilst developing the systems and workforce to support this change.

Illustration 2.7b

1. Commissioning Evidence-Based self-care
Giving people with long term conditions the skills, confidence and support to self manage.

2. Clinician Training
Helping clinicians to develop the skills, knowledge and attitude to support and motivate people with long term conditions.

3. Changing health systems
So that they encourage and facilitate self-care.

2.8 References

1/ The Health Foundation (2011). Helping people help themselves. Available online at: http://www.health.org.uk/areas-of-work/research/helping-people-help-themselves/

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PART II
BUILDING AN EVIDENCE BASE

CHAPTER 3 / CALL FOR EVIDENCE

3.1 Initiating the Call for Evidence

3.2 QUESTIONS:
3.2.1 *How do we deliver the different elements of the House of Care Model?*
3.2.2 *What additional issues need to be taken into account?*
3.2.3 *How can organisations work together to support young adults?*
3.2.4 *How can organisations give young adults more control over their care?*
3.2.5 *What barriers need to be addressed?*

3.3 Summary of Outcomes

3.4 List of Respondents

3.1 Initiating the Call for Evidence

Building on the task set by the Senate Council and the approach outlined by the Programme Board, the *Evidence Review* provided an outline of the current organisational and policy context within which a framework for commissioners would be built.

In order to validate this context and identify any strategic issues that would impact the creation of a framework, as well as highlighting examples of success in supporting young adults to self-care — a *Call for Evidence* was published in February 2015.

In addition to gathering evidence and examples of good practice, the Call for Evidence aimed to drive the programme forward by identifying partner organisations, at the community level, to co-host and lead on the subsequent engagement phase of the project.

Given the range of organisations that work with young adults in London, the Call for Evidence was circulated widely to both statutory health bodies and community organisations, with a request to re-circulate the Call through their networks.

To ensure a standardised response, five questions were selected for consultation; these were:

1/ From your experience how do we effectively deliver the different elements of the House of Care Model and the model as a whole?

2/ What are the additional areas/ issues we need to take into account?

3/ How should organisations, public sector professionals, community groups and young adults, work together to support young adults to set their goals?

4/ How should organisations give young adults control of their support and care planning?

5/ What barriers need to be addressed?

This chapter is organised into five main sections, based on the questions above, and presents the combined feedback received from the Call for Evidence.

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3.2.1 How do we deliver the different elements of the House of Care Model?

WHOLE MODEL

New Models of Care

> *"Traditional models of care are at times not relevant to our child and adolescent population who can live chaotic lives and need support to develop into motivated, self-caring young adults. We need ways to deliver care in a more patient-focused way. This requires* ***an individualised approach to goal-setting and treatment*** *planning, as it increases adherence and engagement, in addition to improving patient experience."*

Call for Evidence / FEEDBACK

1/ ***How do we effectively deliver the different elements of the House of Care Model and the model as a whole?***

Envisioning a Holistic Framework

> *"Rehabilitation focuses not only on the person's health but on helping them live fulfilling lives in terms of education and employment, finances, relationships, psychosocial and physical aspects of daily living.* ***For rehabilitation to be effective, it needs to take place within an holistic framework, necessitating multi-professional engagement*** *and joint-working."*

COMMISSIONING INCLUDING "MORE THAN MEDICINE"

Rethinking Commissioning

> *"Responsive commissioning which is evidence based, clinically and need led should identify opportunities and pathways for self-care. New models of care and joint commissioning with partner commissioning bodies will enable greater opportunities to further develop and embed self-care for young adults. To do this,* ***commissioners will need to work in partnership with patients and clinicians****."*

3.2.1 How do we deliver the different elements of the House of Care Model? ... cont'd

ORGANISATIONAL & SUPPORTING PROCESSES

Call for Evidence / FEEDBACK

1/ *How do we effectively deliver the different elements of the House of Care Model and the model as a whole?*

"The Need for an Integrated Approach

Organisational processes should be flexible and responsive to fluctuations *in need for self-carers. An integrated approach with user involvement in the design of services is necessary for services to be successful. Senior buy-in is imperative to successful implementation when introducing new models of working."*

"Using Social Media to Provide Support

Patients have taken part in the design and development of a new approach to interacting with our adolescent patients with Diabetes, using a Whats App (broadcast) group to motivate over 11 year olds. It aims to ***create a supportive virtual community for patients****, and to bridge the gaps between appointments and improve self- motivation and positive self-care behaviours."*

"The Right information at the Right Time

Patients and their families' value having ease of contact with appropriate professionals, so we have a ***service that allows easy access into the service (including self-referral) at any point during the treatment pathway*** *– and beyond. They want to receive information at the right time for them, and need differing formats of information provision."*

"Creating Joint Pathways of Care

Greater association between health and local councils/facilities planning enables access, and the creation of joint pathways of care. ***A shared building for health and social care services and other stakeholders e.g. education, supports collaborative working****. Transition specific therapy posts to be funded across MDT therapies for CYP with long term disabilities. A key role of allied health professionals (AHPs) is with regard to sign-posting to relevant services, and ensuring effective communication between clinicians and providers to enable seamless transition of care."*

3.2.1 How do we deliver the different elements of the House of Care Model? ... cont'd

HCP PROFESSIONALS COMMITTED TO WORKING IN PARTNERSHIP

Call for Evidence / FEEDBACK

1/ **How do we effectively deliver the different elements of the House of Care Model and the model as a whole?**

"Enabling Consistent Care

GPs need to be active participants in the care of the patients when they are children. More frequently the children with long term conditions are managed exclusively by hospital specialists for the first 16 to 18 years of life and then are effectively jettisoned into the world of adult healthcare with the GP having to pick up the pieces from an ill-informed position."

"Creating a Space for Knowledge Sharing

Greater emphasis on MDT education and prognosis informs more holistic goal setting and improves engagement across the years. Weekly formal meetings as a wider MDT, with regular informal discussions, to ensure a holistic approach to care, and allow sharing of expertise and knowledge. A willingness and interest from local clinicians has led to a range of successful programmes of self-care e.g. for diabetes."

"Working in Partnership

We have developed a model of care for paediatrics to work in a more integrated way. Connecting Care for Children brings together the whole system of child health centred around the GP practice. It provides better access for children and families to their GP and for GPs, health visitors and other professionals to specialist paediatric services. It works with communities, local champion groups and new practice champions to release the resourcefulness of the community to feel confident to manage conditions themselves and more in partnership with clinicians and health professionals when necessary."

3.2.1 How do we deliver the different elements of the House of Care Model? ... cont’d

ENGAGED, INFORMED INDIVIDUALS & CARERS

Call for Evidence / FEEDBACK

1/ ***How do we effectively deliver the different elements of the House of Care Model and the model as a whole?*** ?

“The Case for an Early Start

Information and education should be delivered at the right time and in the right format for the individual patient and their family and use the range of digital technology, to keep them informed and to allow them to make informed choices. ***Our evidence indicates that young people should be involved from the age of 12*** *years and that starting at 16 years of age is too late.* ”

“Co-Designing Resources

Building on the relationships we have made, we are ***working with our local communities to co-produce resources that empower families to self-care*** *for minor conditions and know when to seek expert help. A fun heuristic called Fix Freddie! (puppet show events) instigates a conversation around where to seek help for common minor conditions that end up coming to A&E for advice.*

We continue to arrange events locally and are developing a toolkit with the puppet company to enable other groups to use the idea. Though the messaging is aimed at children it can reach the wider family and community, and inform the way we work with all patient groups to become facilitators of their health rather than paternalistic in providing care. ***Information and education resources that are co-designed and co-developed will have the most impact and sustainability****.* ”

3.2.2 What additional issues need to be taken into account?

Call for Evidence / FEEDBACK

2/ **What are the additional areas / issues we need to take into account** ?

ISSUES (i)

“ *Health services need to move forward alongside other industries using* **technology and social media to support patients**. *Studies have shown that up to 40% of patients find information on social media to deal with their health related issues. However many clinicians worry about delivering advice through these methods, voicing concerns such as confidentiality and consent.*

There is a need for a **cultural change amongst some clinicians** *and healthcare providers in order for self-management to become embedded in routine healthcare systems.* ”

(ii) IDEAS

“
- **Confidence building** for parents and young people
- Peer support networks and use of digital technology for **self-education, networking and communication**.
- **Rehabilitation professionals are key** to championing and delivering self-management for young people with long-term conditions. These skills are already integral to their core skill-set, but it will require increased recognition of the role they can play in self-management.
- **Self-management should start at diagnosis and continue throughout treatment** and beyond, especially as more young people survive cancer and need to develop the skills to live long-term with the consequences of their diagnosis and treatment sequelae.
- Education. **Better access to information** is needed to instill knowledge around their condition and self-advocacy. Leaflets and information packs are no longer relevant for children and young people, using appropriate language and resources is the way forward.
- **Streamlining services for children with chronic diseases**, reducing unnecessary appointments, inefficiencies and missed school. ”

3.2.2 What additional issues need to be taken into account? ... cont'd

Call for Evidence / FEEDBACK

2/ *What are the additional areas / issues we need to take into account* ?

(iii)

EXAMPLES OF GOOD PRACTICE

“

- **Flexible Appointments /** Hillingdon hospital has set up diabetic clinics in schools, reducing time away from lessons from 5 hours to 30 minutes and increased clinic attendance from 70-98%. Patients find appointments at venues outside hospital beneficial and health-care workers have highlighted these interactions can be more useful and relevant to patients e.g. sessions at home where the dietician can advise parents whilst cooking about Carb-counting meals and build up relationships and trust.
- **Promoting Self-management /** Self-management-focussed interventions can improve cancer outcomes and quality of life (Stinson et al, 2012). Self-management can encompass a variety of topics (including vocational rehabilitation, physical activity, fatigue and anxiety management amongst others) and we are currently working to build this into the regular treatment programmes for young adults.
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3.2.3 How can organisations work together to support young adults?

Call for Evidence / FEEDBACK

3/ **How should organisations, public sector professionals, community groups and young adults work together to support young adults to set their goals?**

ISSUES (i)

“ ***Better-established routes of communication*** *are needed across sectors and between providers for ‘Hub and spoke’ models of care to be effective.*

Evidence Based Practice *pathways need to be designed and implemented across organisations, with audit used to inform future delivery.*

The CAF (Common Assessment Framework) is a useful tool for bringing organisations together but experience within an education based setting has presented a ***lack of collaborative thinking*** *in a formal setting.* ”

(ii) IDEAS

“
- The Care Act places preventative health duties on commissioning bodies. **Developments in local authority services** (especially in relation to transition) could also support the self-care agenda.
- Joint children's commissioners support joint commissioning arrangements across CCGs and local authorities, and provide significant opportunities to **plan and commission services with and for young people** to maximise personal control and choice, and building into other interdependencies such as education, employment and care.
- Commissioning specific services such as **Information, Advice and Support** (IASS) provide support to young adults to set their self-care goals.
- **Engage patients in shaping their healthcare** via co-production. Services need to be set up in collaboration with all the stakeholders including patients, healthcare staff and commissioners.
- Utilise **person-centred assessment tools**, to enable meaningful goal-setting and treatment planning. Tools such as the Canadian Occupational Performance Measure enable young people to set their own priorities for rehabilitation, and serve as a patient-reported outcome measure enabling effective evaluation of the service.
- Young people facing emotional/mental/physical health concerns should have an opportunity to access a Looked After Child support structure, with a lead professional and a specialised team supporting the young person. This **team of mentors** will support the young person in setting, reviewing and meeting targets. This in time allows the young person to develop the autonomy needed for self-care. ”

3.2.3 How can organisations work together to support young adults?

Call for Evidence / FEEDBACK

3/ *How should organisations, public sector professionals, community groups and young adults work together to support young adults to set their goals* ?

(iii)

EXAMPLES OF GOOD PRACTICE

“

- **Arts & Media /** Within the diabetic service at Ealing we plan to use graphic facilitation to further help children articulate their ideas, brainstorm and unpick issues.
- **Communication /** 'Better Conversations' (http://talklab.nhs.uk/) is a whole system approach to improving the consultation between young people and health care professionals co-produced with young people.
- **Training /** Training materials for a set of inter professional training workshops for health care professionals co-produced with young people, and designed to support them through transition are at (http://www.talklab.org.uk/projects/hee/ the password for films is 'fish').
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-

”

3.2.4 How can organisations give young adults more control over their care?

Call for Evidence / FEEDBACK

4/ *How should organisations give young adults control of their support and care planning* ?

ISSUES (i)

> *There are **training implications for clinical staff** in relinquishing expert control over patient health.*

IDEAS (ii)

- In respect of young people with Education, Health and Care Plans (EHCP) this should be incorporated into their EHCP assessment. This could include use of Personal Health Budgets in some circumstances.
- Guidance on how **health professionals and parents collaborate** to use Education, Health & Care Plans (EHCP) effectively.
- Initially by education and informing e.g. **expert patient programmes**.
- **Motivational 'apps'** could be devised similar to those used in fitness to support children to set their own goals.
- Utilising **peer networking** at a young age.
- Regular user involvement at an organisational level.
- Address the wider barriers and be **holistic in approach** e.g. address community mobility and access within the community with the wider workforce and outside agencies.
- Maximise **engagement** and adherence by involving young people in research and audit and then implement their views into service design.
- Implement **holistic needs assessment** as part of routine care to ensure that treatment is truly person-centred, and can address the entire range of their needs (rather than simply focussing on their physical or most 'visible' needs).

3.2.4 How can organisations give young adults more control over their care?

Call for Evidence / FEEDBACK

4/ ***How should organisations give young adults control of their support and care planning*** ?

EXAMPLES OF GOOD PRACTICE

(iii) “

- **Self-advocacy** / Our transition service pathways include health plan interviews with Young People with neurological disabilities. They are frequently unable to explain their condition and its medical management. Self-advocacy and confidence to lead in these areas becomes increasingly important as the young person is transitioning to adulthood so they can take control of their health management as adults.
- **Monitoring** / Service user questionnaires following specific group interventions to assess their impact.
- **Co-Creation** / We have consulted the young people receiving their treatment at the UCH Macmillan Cancer Centre, as part of our scoping project in order to enable them to shape and co-create rehabilitation and self-management services.
- **Self-Referral** / The access to therapeutic support from the Well Centre has benefited the school immensely. The opportunity to develop self-care among the more emotionally vulnerable students was noticeable here as young people have organised their own appointment times and self-referred based on literature, posters and presentations regarding the WC services. This collaborative approach has benefited young people, families and both organisations.
- **Transition Support** / We co-produced a programme with young people, designed to support them through transition, publishing an app to support the programme for young people (play.google.com/store/apps/details?id=com.talklab). ”

3.2.5 What Barriers Need to be Addressed?

Call for Evidence / FEEDBACK

5/ What barriers need to be addressed ?

(i)

ISSUES

“*There needs to be an accepted standard of care across all sectors, with a strong emphasis on the importance of prioritising self-management as an expected component of treatment.*

Perverse funding incentives in the way of the traditional commissioning model has posed the biggest challenge to being more integrated and innovative. These financial disincentives need to be removed.

Self-management needs to be addressed within primary, secondary and tertiary care settings, but at the current time there are significant gaps in service provision which impact on the quality of transition between services and sectors. In particular access to community services both physically and financially.

Education of the CYP and parents, including training for parents/carers to address parental anxiety and confidence in their child's self-care and responsibility for self-care.

Guidance on how to assess capability to self-care.

Placing greater emphasis on prognosis at the time of diagnosis (when young if possible) to manage expectations and goal setting.

Time of healthcare staff.

The development of fully integrated services so person-centered care is not stifled by separate budgets and pressures on resources.”

3.2.5 What Barriers Need to be Addressed?

Call for Evidence / FEEDBACK

5/ *What barriers need to be addressed* ?

(ii)

IDEAS

“

- Designing services around information gathered from audits of yearly health plans.
- Raise the profile of AHPs to empower patients, and their families, to manage their own condition.
- The unavailability of age-appropriate services and resources in their local community disadvantages young people. Making additional resources for community rehabilitation services available would continue the work started in hospital, in a timely and effective manner.
- Resources and funding for administration staff to give better access for patients and healthcare workers would significantly streamline services.
- Training for professionals on appropriate use of technology and social media to enable services to be developed.
- The barriers to organisations working together may be an overwhelming support structure with too many professionals in place, taking the independent self-care skills away from the young person. A clear assessment and review of specialist support by the lead professional could overcome any potential of an overflowing body of support.
- We are working with our commissioners and partner organisations to navigate a sustainable way to counter perverse funding incentives and provide a more seamless system for our local population. We have started to look at our population in segments that will facilitate being both reactive by providing services that are needed for certain groups and also proactive in keeping groups healthy and well. ”

3.2.5 What Barriers Need to be Addressed?

Call for Evidence / FEEDBACK

5/ What barriers need to be addressed?

(iii)

EXAMPLES OF GOOD PRACTICE

“

- **Empowering Young People** / Many young people do not have a full understanding of their condition and its management as a result of parents taking responsibility of these roles on behalf of their children. In response, an education group is empowering young people with knowledge of their condition, so they can go to adulthood understanding how to optimize their self-care and function. Using workshops and peer support, the young people also lead in the design, production and execution of an educational DVD. The impact will be to reach out to a wider community who can use it as an information resource.

- **Integrating Services** / A transition forum to address fragmentation between paediatric and adult services.

- **Transition Support** / Capacity building through therapy provision. Having a transition therapy post to address transition and self-management issues of people aged 14-18yrs.

- **Creative Solutions** / The lead physiotherapist is investigating access to exercise on prescription with community leisure services. ”

3.3 Summary of Outcomes

The responses to the Call for Evidence supported the use of the House of Care Model as the basis for developing a self-care framework for young adults.

Illustration 3.3a shows the key recommendations from the Call for Evidence mapped onto the House of Care Model, demonstrating how the different elements of the model are essential components for the successful development and implementation of the proposed self-care framework.

Respondents also provided examples of good practice, ideas, and issues relating to the consultation questions, which validated the programme's approach to developing a framework. The feedback not only helped to define the framework in greater detail, but it also informed the subsequent engagement events.

The four key issues that were highlighted by the responses are:

1/ The importance of involving patients and the public in the design and development of services and the production of educational and support tools;

2/ The need for services that are more patient-focused and holistic in their approach to treatment and support;

3/ The need for education and training for professionals and patients in order to change the culture of organisations and enable adoption of self-care programmes; and,

4/ Multi-professional collaborative working that looks beyond the disease/condition and crosses the commissioner/provider/patient boundaries.

The responses highlighted several examples of good practice in the case of individual services that had worked collaboratively with patients to enable a co-ordinated multi-professional response in meeting an individual's needs. There was, however, a lack of evidence to suggest that this approach was widespread across and within organisations and communities.

Nevertheless, the success of these services, in a range of different contexts, indicated that there was the potential of universal applicability of their approach, but that there were still significant issues that would need to be addressed locally to facilitate this.

While the responses to the call for evidence provided valuable insight, their almost universal organisational bias meant recommendations based solely on this type of input would ignore the voice of patients and fail to fully reflect the outcomes valued by service users. Greater

3.3 Summary of Outcomes ... cont’d

collaboration by these organisations in co-producing their responses with patients would have demonstrated that they were operating in a truly transformational way as required by the House of Care Model.

Therefore, further engagement with young adults with LTCs and their carers was required to validate the viewpoints and provide further detail on how they would impact on patients and the public.

3.3 Summary of Outcomes

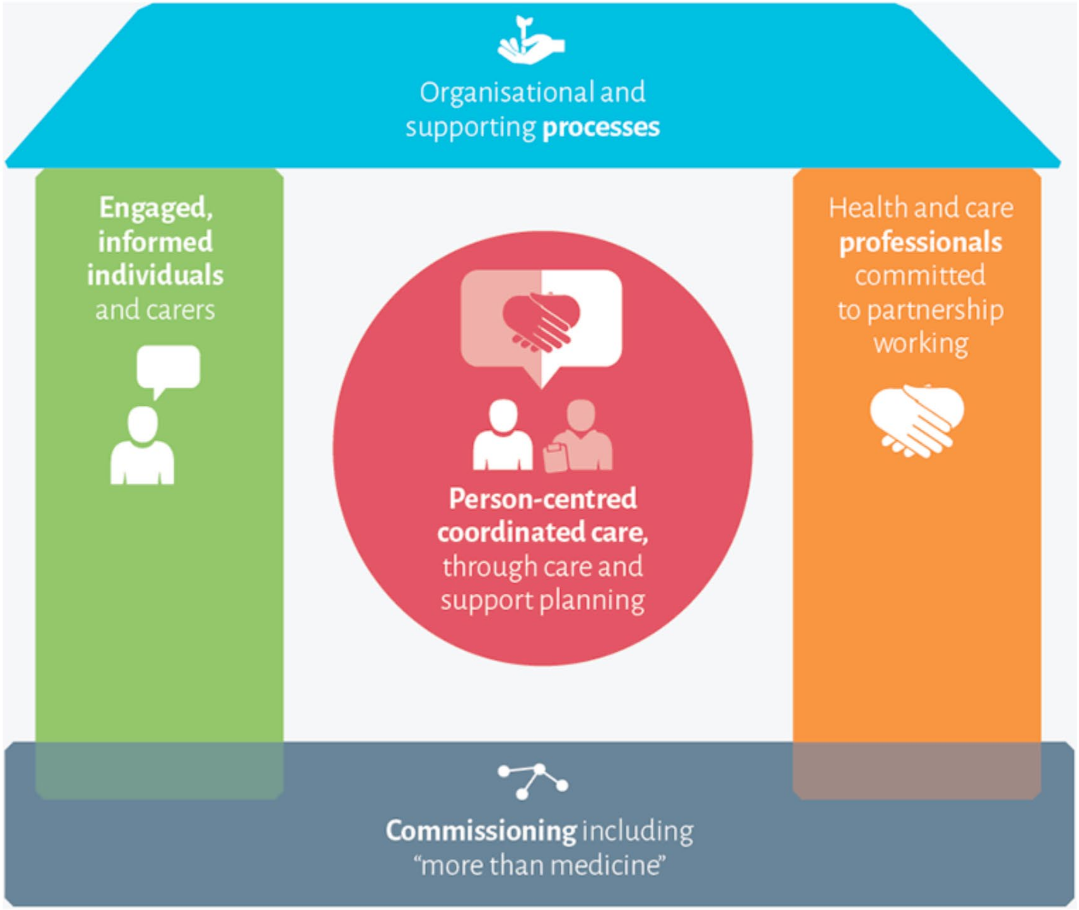
Illustration 3.3a /
Key recommendations from the Call for Evidence mapped onto the House of Care

Funded transition specific therapy posts

Shared facility for health and social care services

Flexible, responsive and integrated approach

Joint pathways of care



Social media / new techs to create supportive virtual communities

Provision of information at the right time and right format

Use of social media / new techs to improve self-care behaviours

Easy access into the service including self-referral

Empower people to self-manage

Self-management assessment tools from early age (at least 12 yrs)

Co-design information and education resources

Ongoing support through transitional periods

Individualised approach to goal setting and treatment

Holistic framework that encompasses 'health & wellbeing'

Multi-disciplinary engagement

Communication between partners to enable seamless transition of care

Active participation of GPs in care of patients from an early age

Senior buy-in when introducing new models

User involvement in the design of services

Joint commissioning with partner organisations

Fostering partnerships with patients and clinicians

3.4 List of Respondents

Vicky Mason, *Children's Commissioner for Redbridge, Barking and Dagenham, Havering and Redbridge Clinical Commissioning Groups /*
Experience of commissioning services for children across North East London.

Steve Buckerfield, *Head of Children's Joint Commissioning, Children's Joint Commissioning Team, North West London Collaboration of Clinical Commissioning Groups /*
Experience of commissioning services for children and young adults in North West London.

Dr Francesca Cleugh, *Consultant, Paediatric Emergency Medicine,*
Dr Mando Watson, *Consultant Paediatrician,*
Imperial College Healthcare NHS Trust /
Experience in North West London of developing a model of care for paediatrics, Connecting Care for Children (CC4C), that puts children, young people and their carers at the heart of healthcare delivery in a more connected and integrated way.

Sarah Blackstock, *Paediatric ST4, Ealing Hospital, London North West Healthcare NHS Trust /*
Experience of diabetic services at Ealing Hospital.

Dr Sara Hamilton, *Paediatrician, The Whittington Hospital NHS Trust /*
Experience of projects helping to improve consultation between clinicians and young people, and a specific focus on transition arrangements.

Catherine Lomas, *Transition Physiotherapist, Hackney Ark Child Development Centre, Homerton University Hospital NHS Trust*
Experience of how the children's therapy services give young adults control of their condition, including a specific example of a new service for people with Cerebral Palsy.

Gemma Lindsell, *Occupational Therapist*
Jenny Appleby, *Physiotherapist*
Teenagers and Young Adults Oncology and Haematology Service, University College Hospital, London
Experience from scoping how the rehabilitation services for teenagers and young adults at the UCLH Macmillan Cancer Centre should be delivered.

3.4 List of Respondents ... cont'd

Hemant Patel, *Pharmacist and Secretary, North East London Local Pharmaceutical Committee (NELLPC) /*
Experience of a new practice designed to help patients take responsibility and manage their long term conditions better with help from pharmacists.

Mohamed Abdallah, *Director of Student Engagement, Dunraven School /*
Experience providing a range of support services to students, including after-school counselling and peer support, and helping students manage LTCs within the context of their daily lives.

PART II
BUILDING AN EVIDENCE BASE

CHAPTER 4 / ENGAGEMENT WORKSHOPS

4.1 Overview of Workshops

Building on the feedback received during the Call for Evidence, the next stage of the project was critical in engaging young adults themselves and learning about their experiences directly. Not only would this provide an opportunity to ask them how commissioning of services could be better tailored to their needs, but it would also validate/invalidate key evidence that had been collected thus far.

Various organisations across London that were previously identified and had contributed to the Call for Evidence, were now invited to play a central role in the project through co-hosting engagement events that would bring together young adults, carers, frontline staff, and other stakeholders to discuss existing challenges and make recommendations. These organisations were selected on the basis of their existing work with young adults around self-care support.

This stage of the project resulted in five engagement workshops being held across London, all of which were designed and delivered in partnership with different organisations. These include:

South London // Dunraven School
West London // Hillingdon Association of Voluntary Services (HAVS)
North-East London // North East London Local Pharmaceutical Committee (NELLPC)
Central London // King's Cross Brunswick Neighbourhood Association (KCBNA)

The defining characteristic of the workshops was that they were led by young adults from each of these organisations. They played a pivotal role in the events by first undergoing training in key communication skills, and then leading the workshops as co-facilitators. This allowed them to assume a central role in the workshops by defining the agenda and ensuring that the voices of young adults were heard.

The first four workshops were hosted by each of the partner organisations, either at their facility, or at a local community hub. The aim of these sessions was to collaboratively discuss what the term 'self-care' means for young adults, what kinds of services are needed, and how can commissioning for self-care support be improved.

4.1 Overview of Workshops

The fifth workshop, organised by the London Clinical Senate, took place a couple of months after these, and served as a platform to collaboratively review the draft recommendations that were outlined subsequent to the initial four workshops. Young adults, partners, and other stakeholders, who had previously taken part in the earlier workshops, were invited to participate in this additional session and share their thoughts/ideas/suggestions on the proposed next steps, and ensure that the recommendations did, indeed, reflect their feedback.

This chapter presents the combined feedback generated during the workshops, (incorporating suggested revisions from the final workshop) — and summarises key themes and recommendations. It is organised in four sections, which reflect the four co-design sessions that made up the main workshops. The data is presented as objectively as possible, with some clarifications where necessary.

4.2.1 Task 1: Communication 'Bubble' Exercise / Overview

In the first task, participants were asked to describe a conversation between two people, (with one of them being a young adult), where there was felt to be a gap between what they were each saying, and what they were really thinking.

The feedback generated reflected both direct experience, as well as imagined scenarios. The following two illustrations represent a sample of the overall feedback.

4.2.1 Feedback from Task 1: Communication 'Bubble' Exercise

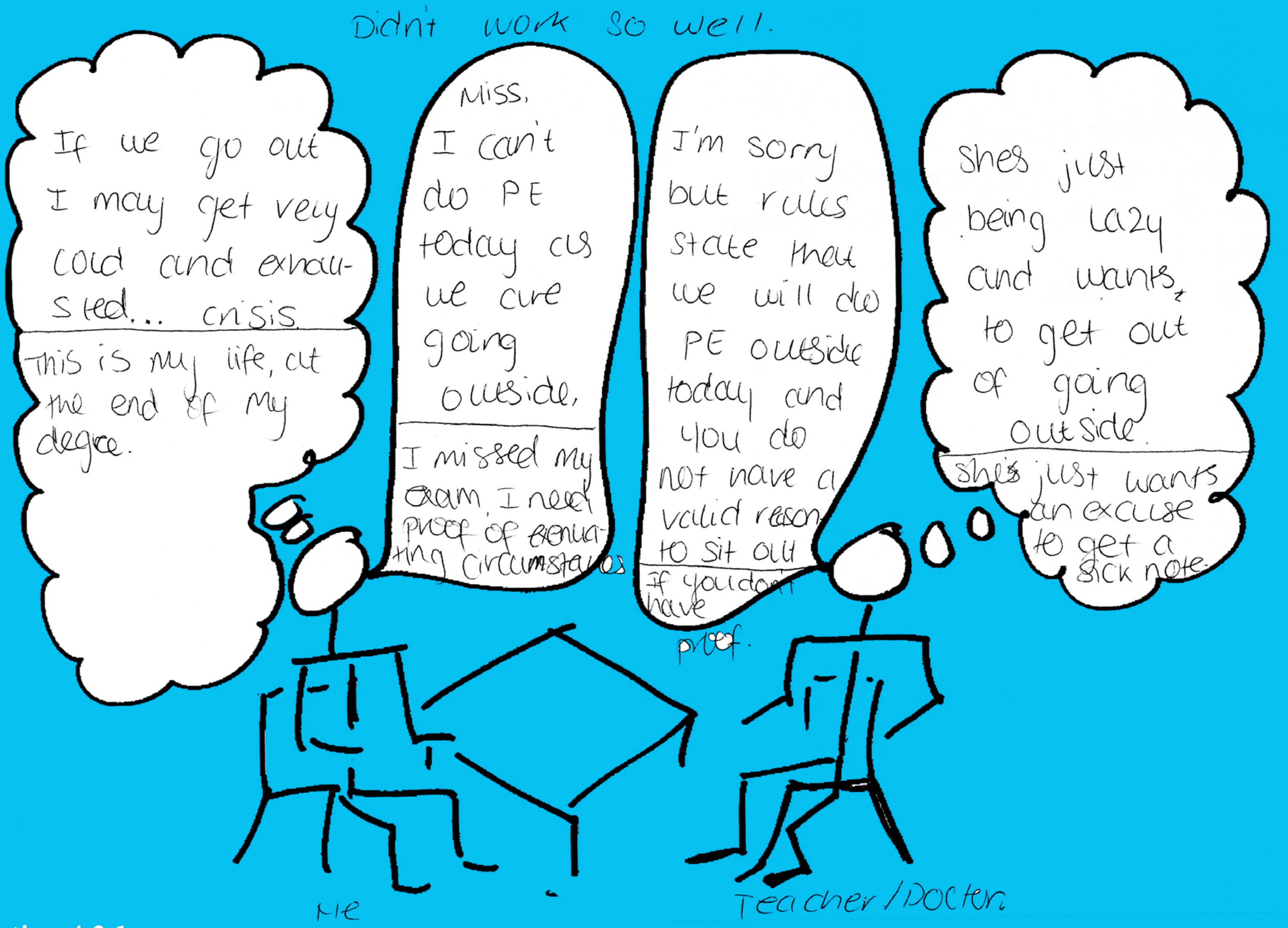


Illustration 4.2.1a

4.2.1 Feedback from Task 1: Communication 'Bubble' Exercise

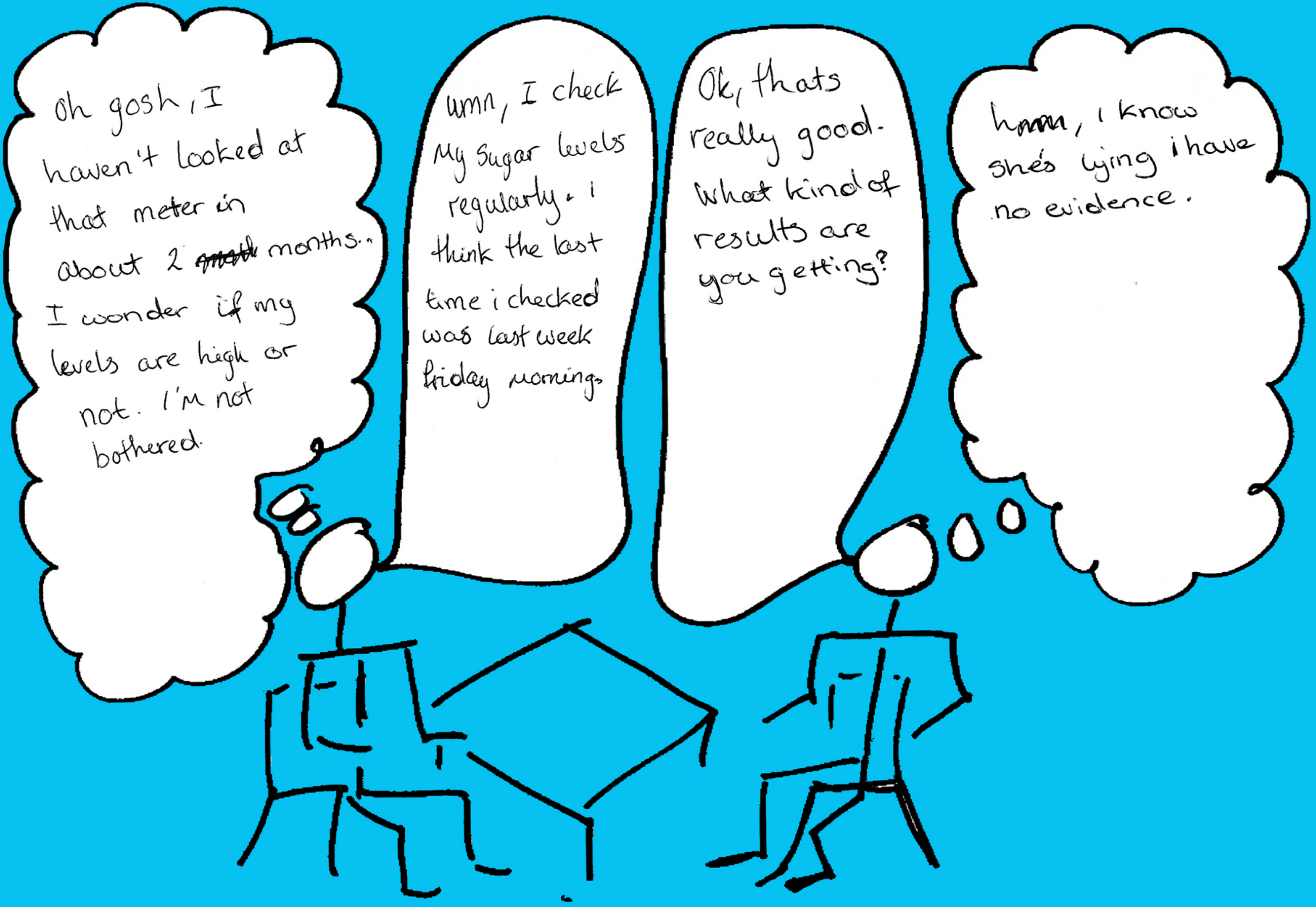


Illustration 4.2.1b

4.2.1 Task 1: Communication 'Bubble' Exercise / SUMMARY of Feedback

The feedback from this task highlighted the different factors that cause a divide between what people say, and what they really think. The results were consistent across all four workshops, and highlighted psychological factors, (e.g. low self-esteem, fear of judgement, fear of failure), in almost all cases. The collective results are summarised below.

Illustration 4.2.1c

4.2.2 Task 2: What do People Need to Feel Supported

The second task comprised of two main areas of questioning:

a) What are the barriers to support? ***and,***

b) What do people need to feel supported?

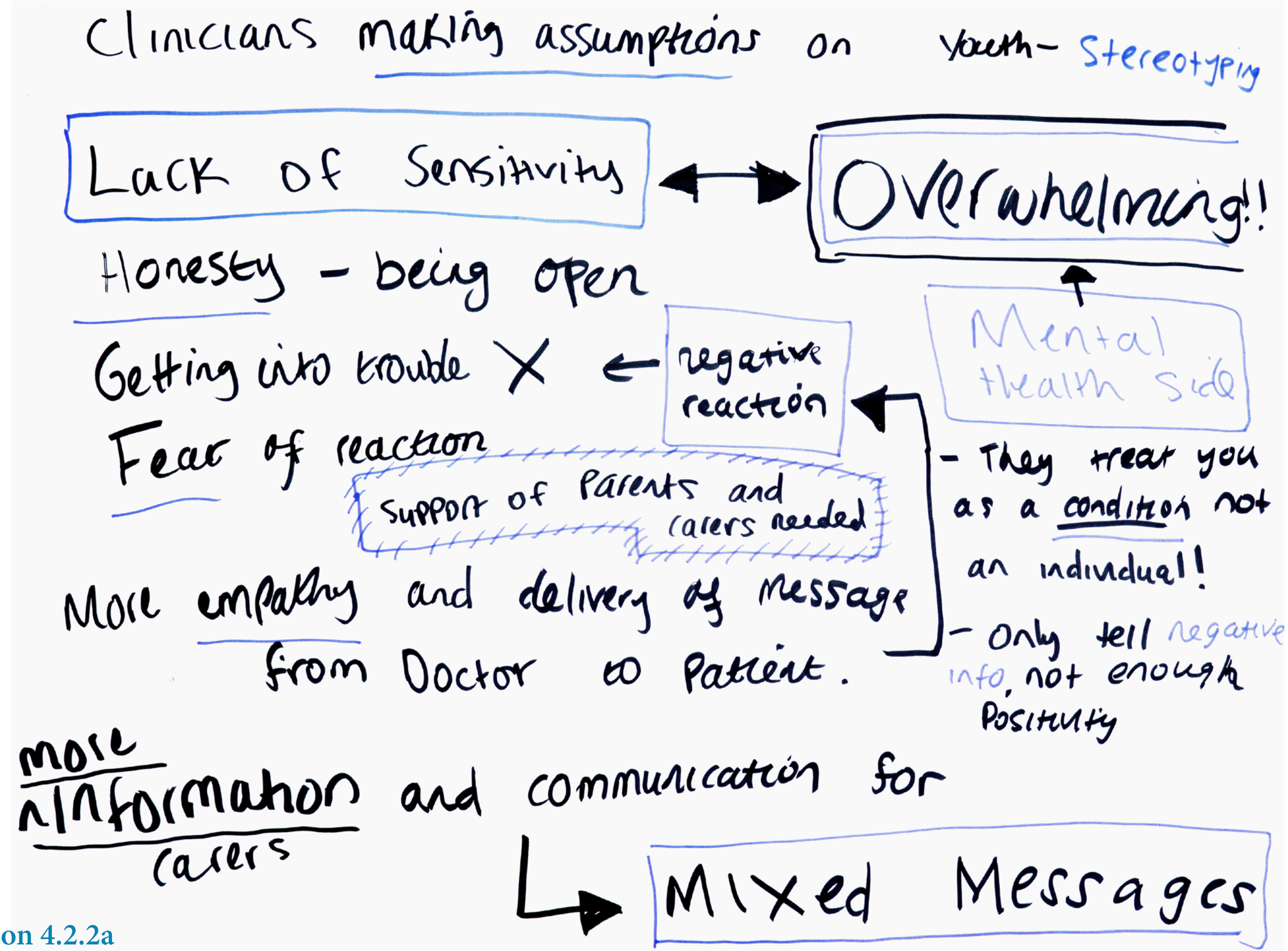
In a couple of the workshops, participants understood these questions as:

a) 'What gets in the way of mastering a (long-term) condition?' and,

b) 'What helps to master a (long-term) condition?'

The following section contains samples of feedback generated during the workshops, followed by two diagrams that summarise key points and recommendations.

4.2.2 Feedback from Task 2: 'What are the Barriers to Support?'



Clinicians making assumptions on Youth - Stereotyping

Lack of Sensitivity ↔ Overwhelming!!

Honesty - being open

Getting into trouble X ← negative reaction

Fear of reaction

Support of Parents and carers needed

More empathy and delivery of message from Doctor to Patient.

Mental Health side

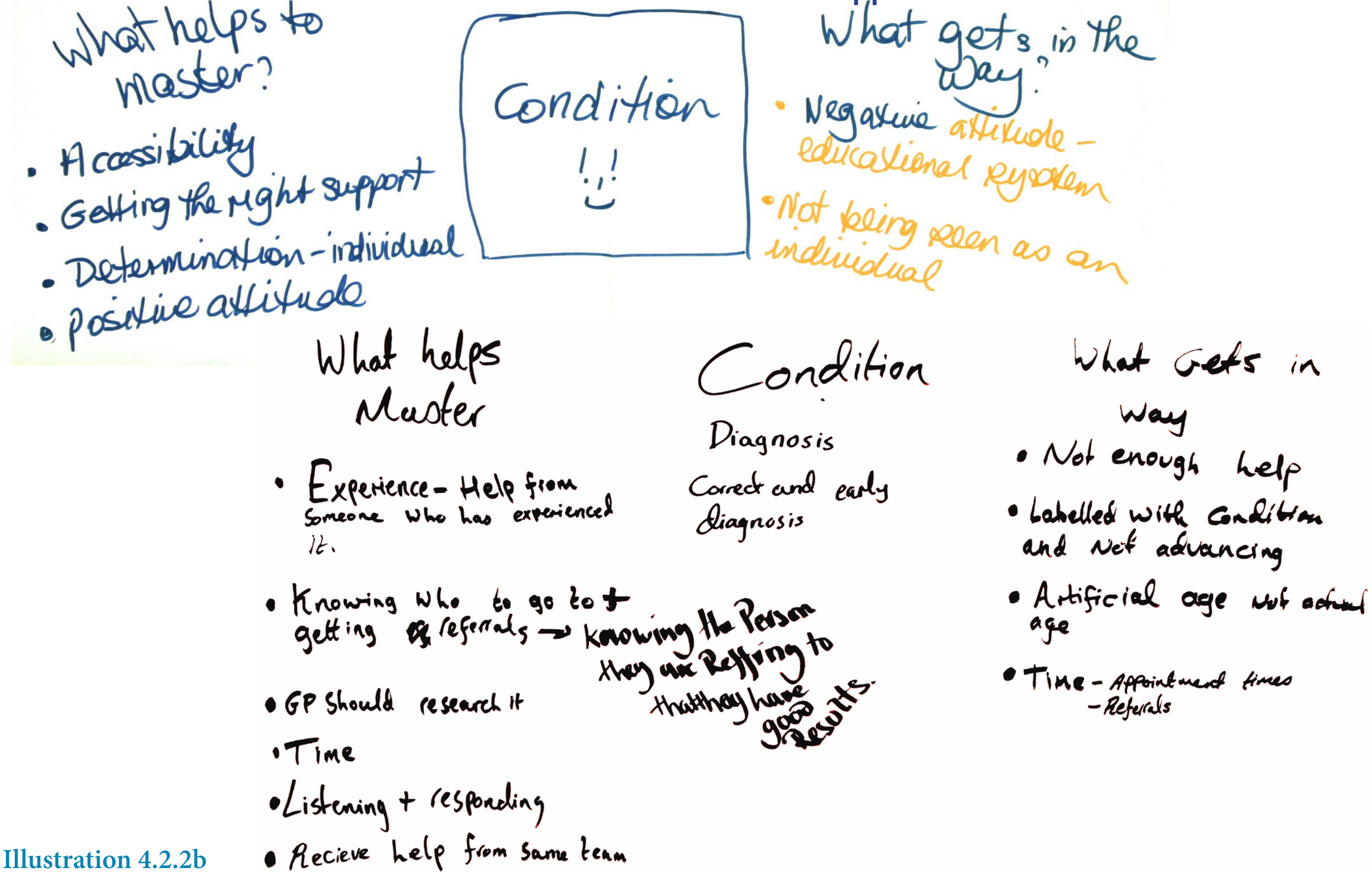
- They treat you as a condition not an individual!
- Only tell negative info, not enough Positivity

more information and communication for carers

Mixed Messages

Illustration 4.2.2a

4.2.2 Feedback from Task 2: 'What are the Barriers to Support?'



What helps to master?

- Accessibility
- Getting the right support
- Determination - individual
- positive attitude

Condition

What gets in the way?

- Negative attitude - educational system
- Not being seen as an individual

What helps Master

- Experience - Help from Someone who has experienced it.
- Knowing who to go to + getting ~~of~~ referrals → knowing the Person they are Reffing to that they have good Results.
- GP Should research it
- Time
- Listening + responding
- Recieve help from same team

Condition

Diagnosis

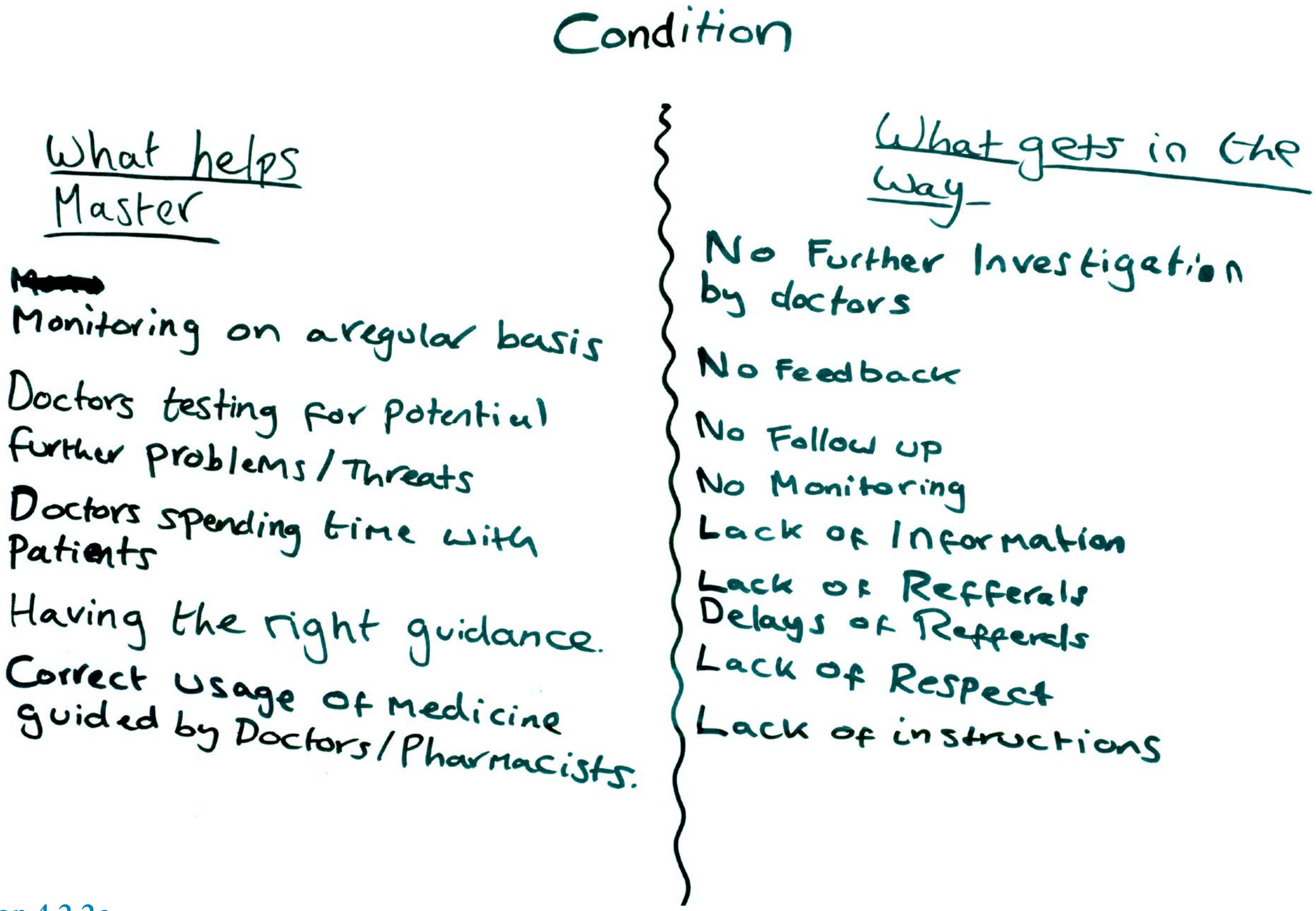
Correct and early diagnosis

What Gets in way

- Not enough help
- Labelled with Condition and Not advancing
- Artificial age not actual age
- Time - Appointment times
  - Referrals

Illustration 4.2.2b

4.2.2 Feedback from Task 2: 'What are the Barriers to Support?'



Condition

What helps Master

Monitoring on aregular basis

Doctors testing for Potential further problems / Threats

Doctors spending time with Patients

Having the right guidance.

Correct usage of medicine guided by Doctors / Pharmacists.

What gets in the Way

No Further Investigation by doctors

No Feedback

No Follow up

No Monitoring

Lack of Information

Lack of Refferals

Delays of Refferals

Lack of Respect

Lack of instructions

Illustration 4.2.2c

4.2.2 SUMMARY of Feedback from Task 2: 'What are the Barriers to Support?'

Negative communication & lack of sensitivity (e.g. HCP, reception staff) //
Lack of flexibility in the system (e.g. delays in getting appointments) //
Not thinking holistically (whole person) //
Rushed appointments / consultations //
Lack of knowledge / information //
Goal(s) of patient not discussed/considered //
Lack of trust and fear of judgement //
Being told what to do, but not how //
Lack of understanding (of condition) //
Lack of respect //
Stereotypes: e.g. age, ethnicity (from media & past experience) //

X *Context*

Clinical [Professional HCP]

Personal [Physical / Emotional]

Lack of confidence and fear of failure and rejection //
Inability to articulate/communicate emotions //
Lack of understanding (of condition) //
Inability to prioritise / make decisions //
Life in general gets in the way (of self-management) //
Insufficient knowledge of available services and support //
Feeling 'forced' (to do/have/be) //
Fear of labels / stigmatisation / stereotyping //
Fear of negative future consequences //

// Peer pressure and fear of stigmatisation
// Other people (who you trust) having bad experiences
// Negative communication & lack of sensitivity (e.g. teachers)
// Lack of flexibility in the system [e.g. missed school]
// Lack of trust (in oneself or others)
// Being told what to do, but not how (e.g. by teachers)
// Lack of understanding (of condition)
// Lack of respect
// Stereotypes: e.g. age, ethnicity (from media & past experience)
// Lack of knowledge / information
// Lack of transparency: lying / hidden emotions / fear of judgement

Community [Psycho-Social]

Context X

Family [Personal Support]

// Parents not listening, just telling you what to do
// Lack of understanding (of condition)
// Lack of awareness of impact of LTC on daily life
// Negative communication & lack of sensitivity
// Lack of transparency: lying / hidden emotions / fear of judgement
// Lack of awareness and poor lifestyle choices (diet. exercise)
// Insufficient knowledge of available services and support
// Lack of respect

Illustration 4.2.2d

4.2.2 SUMMARY of Feedback from Task 2: 'What are the Barriers to Support?'

"They [adults] don't take us seriously."

"[What's important is] being positive and having the support when you are going through a tough time."

"I had to stop my mum coming with me for my appointments because the doctor would ignore me completely and just talk to her. I was 16 and he would still ask her questions like 'What does she eat?' or 'What did she do'. "

"I was in such shock when I first heard I had diabetes. Even my parents were totally shocked ... We didn't know where to go, who to speak to, what to do. The doctors and nurses just told us the diagnosis and left us on our own. I feel there should have been support for both me and my parents."

"You can only take responsibility and be in control of your health if there are services to support you."

"Clinicians tend to give you all the negatives about the condition which makes us feel really down. It is always about what is wrong and what is not working."

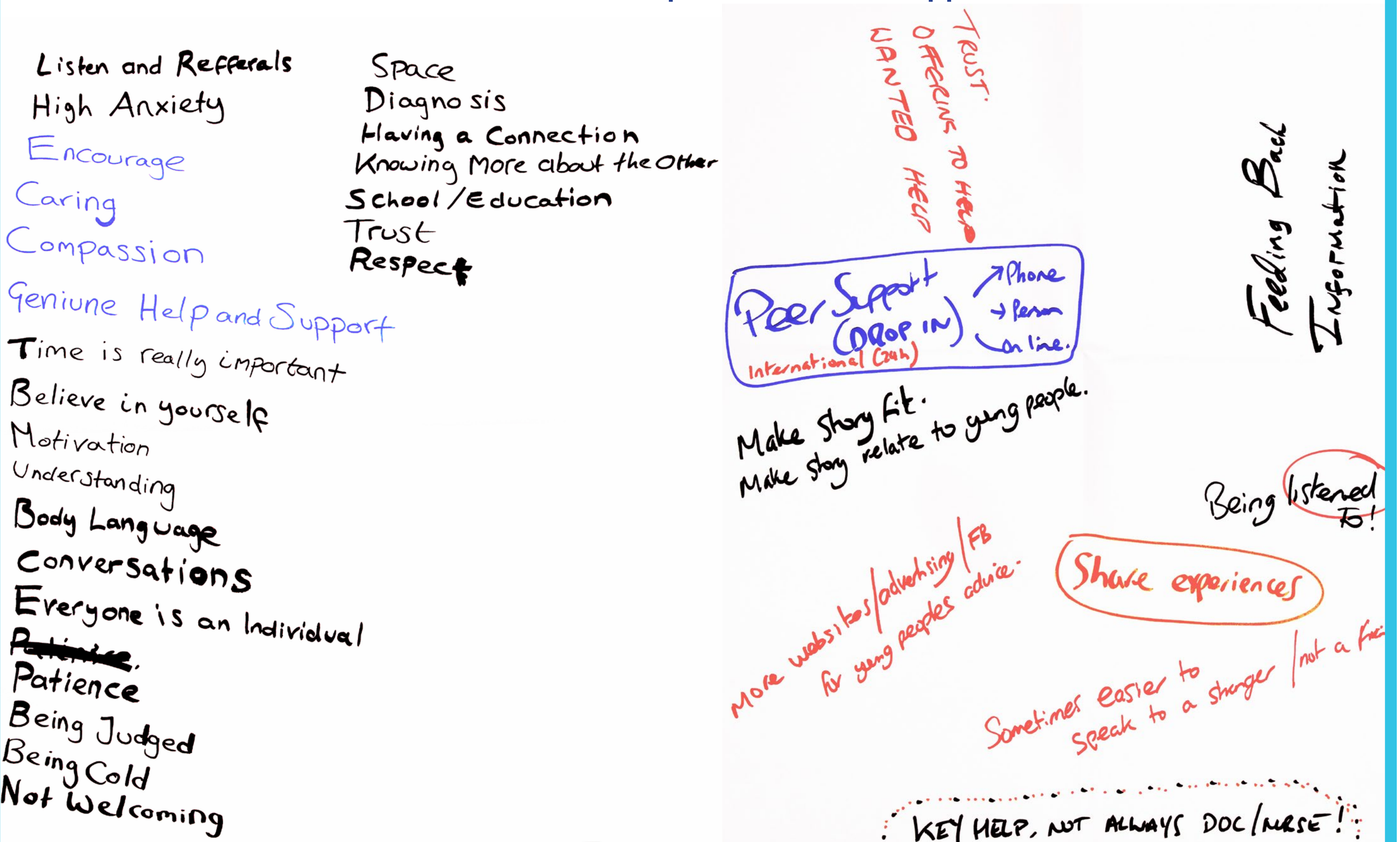
"Clinicians need to treat me like a person. Sometimes they lack sensitivity in how they talk to us [young adults] about our health matters."

"You only see the GP when there is a problem. There is no way of finding out how I am doing and if I am on the right track [the rest of the time]."

4.2.2 Feedback from Task 2: 'What do People Need to Feel Supported?'

Illustration 4.2.2e

4.2.2 Feedback from Task 2: 'What do People Need to Feel Supported?'



Listen and Refferals
High Anxiety
Encourage
Caring
Compassion
Geniune Help and Support
Time is really important
Believe in yourself
Motivation
Understanding
Body Language
Conversations
Everyone is an Individual
~~Patience~~.
Patience
Being Judged
Being Cold
Not Welcoming

Space
Diagnosis
Having a Connection
Knowing More about the Other
School/Education
Trust
Respect

TRUST.
OFFERING TO HELP
WANTED HELP

Peer Support (DROP IN)
International (24h)
→ Phone
→ Person
→ On line.

Feeling Back
Information

Make Story fit.
Make story relate to yung people.

Being listened To!

More websites/advertising/FB
for yung peoples advice.

Share experiences

Sometimes easier to
speak to a stranger/not a fr

KEY HELP, NOT ALWAYS DOC/NURSE!

Illustration 4.2.2f

4.2.2-b SUMMARY of Feedback from Task 2: 'What do People Need to Feel Supported?'

BEING GIVEN THE RIGHT INFO & RESOURCES TO MANAGE CONDITION //
HCPs providing a clear understanding of a condition, what to do and why

BUILDING RELATIONSHIPS w/ GPs and other HCPs //
Working together to set goals through practical resources (not just talking)

RESPECT / TRUST //
Ability to have an open and trusting dialogue with HCPs and creating the conditions that make it safe to share / learn from mistakes, without blame

ACTIVE LISTENING & COMMUNICATION //
Sense of empathy from HCPs and that someone is actually listening (through attentiveness: greetings, eye contact, body language)

TIME //
More time during consultations

ENVIRONMENT //
Create welcoming and comfortable physical environments

KNOWING WHERE TO GET HELP (Signposting) //
Providing information on where to go for additional support

Context

Clinical [Professional HCP]

Personal [Physical / Emotional]

INFORMATION & RESOURCES //
Knowing how to make positive changes [to behaviour/attitude], and understanding how to take of yourself - using resources such as mobile apps, digital media, and other creative ways of sharing information

RESPECT / TRUST //
Trust in yourself and others, acknowledging personal choices and being able to admit when something didn't work and move on

LEARNING TO TAKE RESPONSIBILITY (Resilience) //
Having the confidence in yourself and your ability to self-care, by taking responsibility, and maintaining a strong 'belief in the future'

LEARNING from / SUPPORTING OTHERS //
Getting training and ongoing support to mentor other young adults with similar conditions/in similar circumstances, and having this role recognised

// SUPPORT NETWORKS (Learning by Example)
Having role models with you to provide support / encouragement, learning from each other's experience and helping others by sharing own personal experience

// BUILDING RELATIONSHIPS (w/ Mentors/Teachers/Volunteers/Professionals)
Working in partnership with different people who can help to set goals, monitor a LTC, and understand 'self-care' through practical resources (not just talking)

// COMMUNICATION & INFORMATION
Understanding -- breaking down -- what common terminology actually means, e.g. 'responsibility' / 'risk' / 'expectation', and using language more effectively to convey relevant and appropriate information

// RESPECT / TRUST
Creating the conditions that make it safe to address the 'what's not talked about space,' e.g. admit mistakes, voice different viewpoints, share other concerns, and learn from experience

// KNOWING WHERE TO GET HELP (Signposting)
Providing information on where to go for additional support

Community [Psycho-Social]

Context

Family / Carers [Personal Support]

// RESPECT / TRUST
Parents stepping back and letting young people take the lead

// BUILDING CONFIDENCE
(For young adult) Having someone close provide encouragement and support

// STRENGTHENING RELATIONSHIPS (w/ Parents & Carers)
Working in partnership with parents and carers to set goals, monitor condition, and learn from experience (including learning from mistakes)

// PROVIDING SUPPORT TO PARENTS/CARERS
Providing support (through mentoring) to parents and carers and making sure they have access to the right information and resources, to help them in their role of caring for young adults

Illustration 4.2.2g

4.2.2 SUMMARY of Feedback / Task 2: What do People Need to Feel Supported?

The feedback from this task was not only instructive but also formed the foundation for the successive tasks. The combined results (from all four workshops) began to paint a picture of where and how young adults felt supported, as well as highlighting the different barriers that prevented them from receiving the support they needed.

The main themes that emerged from this task are:

// Young adults need to feel supported in different areas of their life — including at home, at school, college or work, amongst friends, as well as in clinical settings.

// There is a real need to build new / strengthen existing relationships — whether between young adults and HCPs, young adults and teachers, parents/carers, employers, and others who might play a direct/indirect role in providing support. Moreover, these relationships need to be defined by trust and respect, and, importantly, they need to be consistent over time.

// Young adults need help to build their confidence so they can start to manage their own health — oftentimes, they lack the personal skills needed to make choices, take responsibility and be proactive about looking after themselves. This includes helping them to identify their strengths and weaknesses, and developing the courage to learn from mistakes. It also implies greater involvement of young adults in the decision making process, where their opinions and experience are taken into consideration by 'adults'.

// The importance of peer support networks — young adults recognised that they needed support and encouragement from people with similar conditions and/or in similar circumstances, so that they can learn from each other's experience and help one another.

// Having the right information at the right time — There was felt to be a gap in the information and resources currently available (across every context). Young adults stressed the importance of being given the right information at the time of diagnosis (understanding the condition, what to do to manage it, and how); knowing where to get additional help and support; having the resources to monitor a condition over time (not just when there's a problem); as well as rethinking the language that professionals use around health issues (in order to make it more engaging and accessible). The use of digital / social media, mobile apps, and other creative ways of accessing and sharing information was also seen as important.

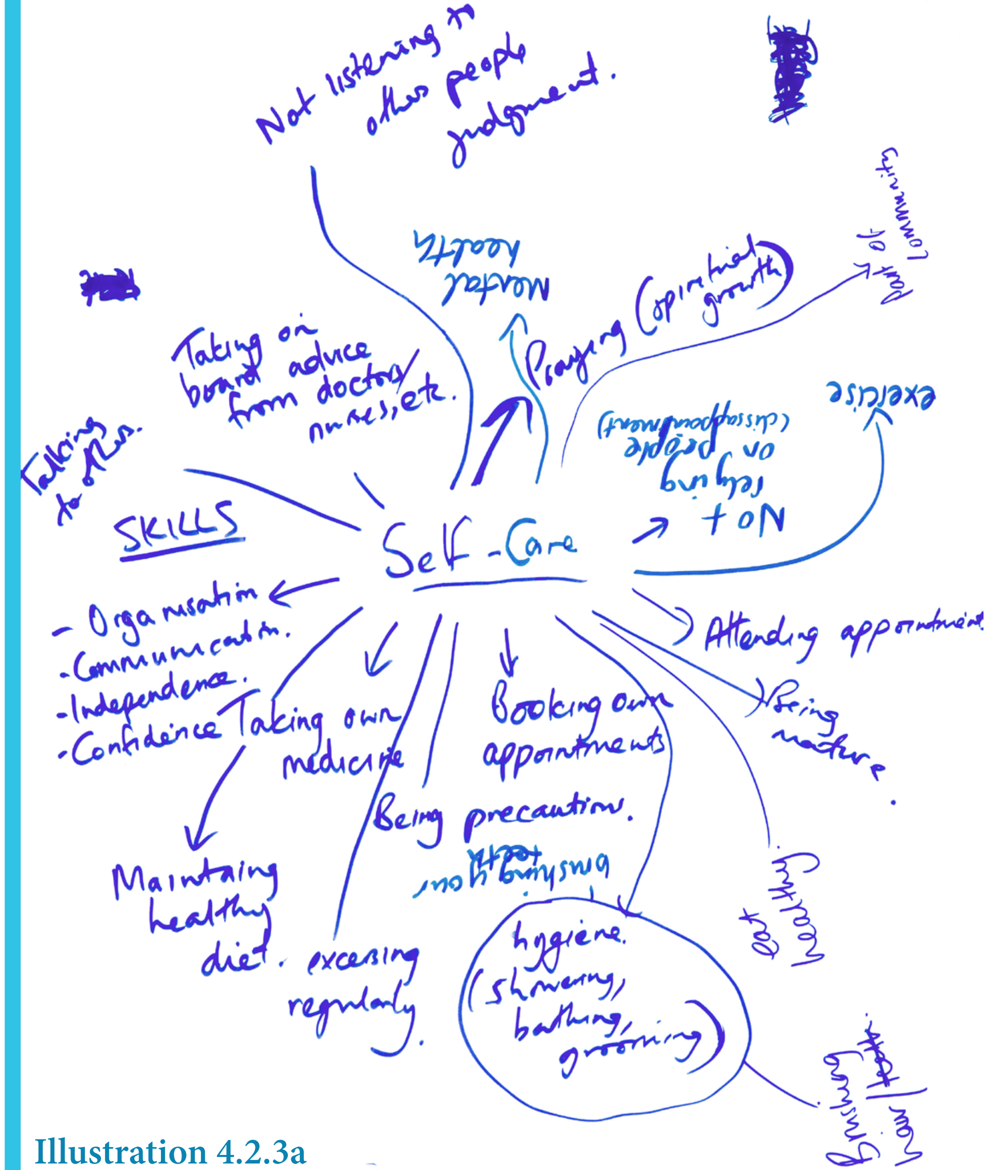
4.2.3 Task 3: How do we Define Self-Care?

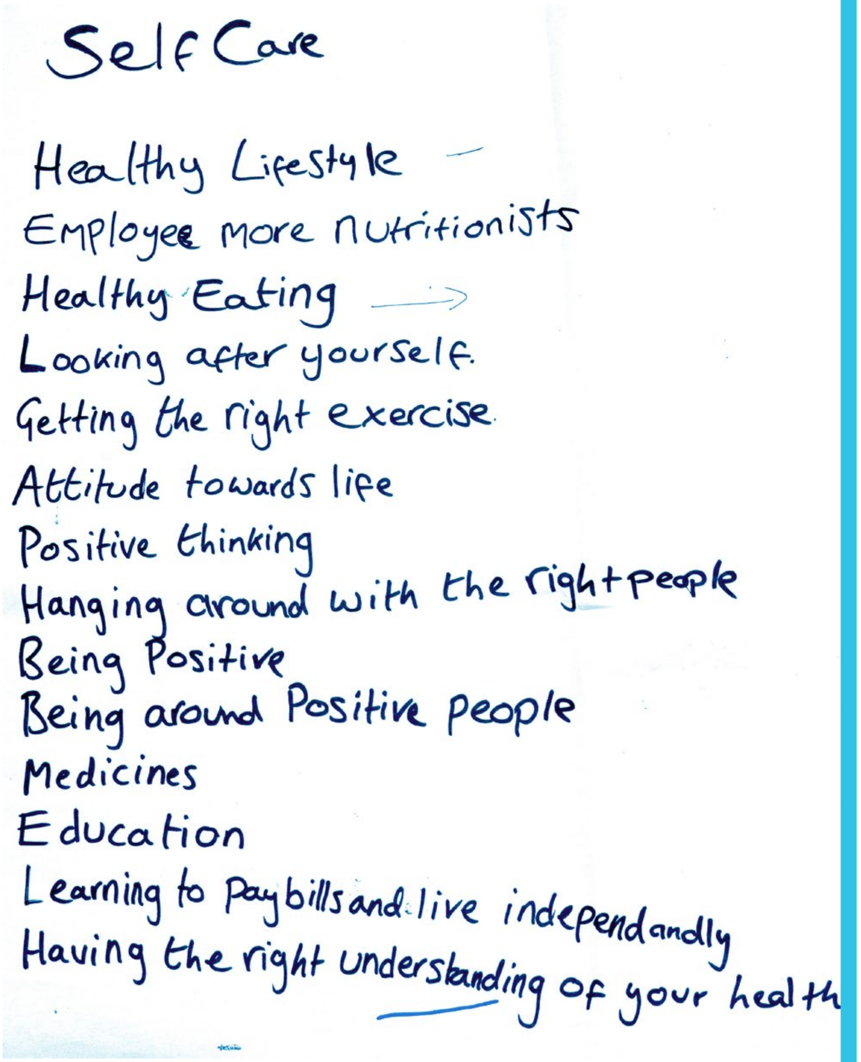
The third task asked participants to define what self-care means to them

self-care

Taking care of self

4.2.3 Task 3: How do we Define Self-Care?




Self Care

Healthy Lifestyle
Employee more nutritionists
Healthy Eating
Looking after yourself.
Getting the right exercise.
Attitude towards life
Positive thinking
Hanging around with the right people
Being Positive
Being around Positive people
Medicines
Education
Learning to Pay bills and live independandly
Having the right understanding of your health

Illustration 4.2.3a

4.2.3 Task 3: How do we Define Self-Care?

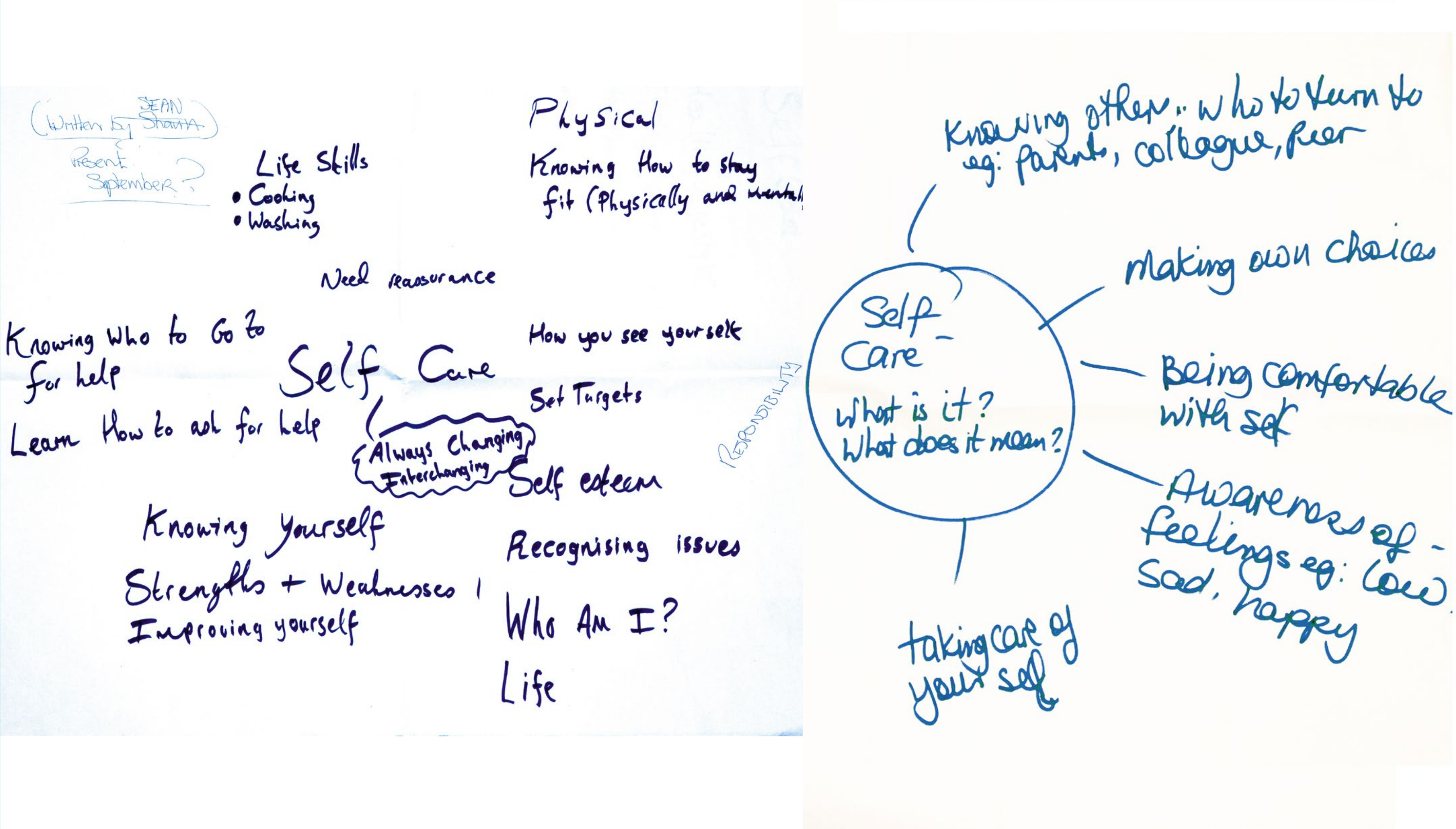


Illustration 4.2.3b

4.2.3 Task 3: How do we Define Self-Care?

Illustration 4.2.3c

“What does Self-Care mean to you?”

“Making decisions for yourself”

“Having the right understanding of your health condition”

“Healthy eating”

“Being able to recognise [health] issues”

“Learning how and where to ask for help ...”

“Taking Responsibility”

“Knowing yourself, and your strengths and weaknesses”

“Accepting your condition”

“knowing who to turn to e.g. parents, teachers, peer network”

“Knowledge and education to self-manage common infections”

“Listening to advice from doctors and nurses and taking precautions”

4.2.3 Task 3: How do we Define Self-Care?

Illustration 4.2.3d

“What does Self-Care mean to you?”

“More confidence in yourself and your ability to self-manage”

“Information & Signposting”

“A Positive Attitude”

“More personalised care”

“Awareness about mental health”

“Having the right services to support you”

“Being part of a community”

“More involvement in decision-making”

“Integrating care with life”

“Being organised, planning and taking medication at the right time”

“Having the abililty and skills to self-manage”

4.2.3 SUMMARY of Feedback / Task 3: How do we define Self-Care?

The third workshop task asked participants to define what the term 'self-care' meant to them.

The outcomes from this task, (across the four workshops), demonstrated that there was no single definition of self-care. Broadly, it was understood as referring to general physical and mental/emotional wellbeing, as well as the ability to deal with day to day life: from positive thinking and recreational activities, to being employed and living independently. The term 'self-care', therefore, meant different things to different people, at different times.

Furthermore, the term took on a different meaning for people who had a health condition (such as diabetes). For these individuals, 'self-care' was closely linked to 'self-management' and the ability to integrate the management of their health into daily life.

The following illustrations bring together the different dimensions of 'self-care' highlighted in the workshops. These include quantitative behaviours such as healthy eating and physical activity, to more qualitative 'ways of being', including attitudes, beliefs, and expectations. It also encompasses the different contexts where self-care might take place, including traditional healthcare settings (GP surgeries, clinics, hospitals), schools, colleges, community hubs (such as youth centres), and other non-clinical settings.

It's important to note that the themes contained in each segment of the 'wheel' are not necessarily exclusive to that dimension alone. It was decided to organise the themes in this way based on the context in which they were mentioned during each workshop. For instance, there are some themes, such as 'Shared decision-making about how to manage LTC', (shown in 'Physical'), that could also be in several of the other segments, e.g. 'Knowledge / Education'.

The illustration, therefore, is intended to represent a conceptual framework that can accommodate many different and overlapping themes into one common model of what constitutes 'self-care'.

4.2.3 SUMMARY of Feedback from Task 3: How do we Define Self-Care?

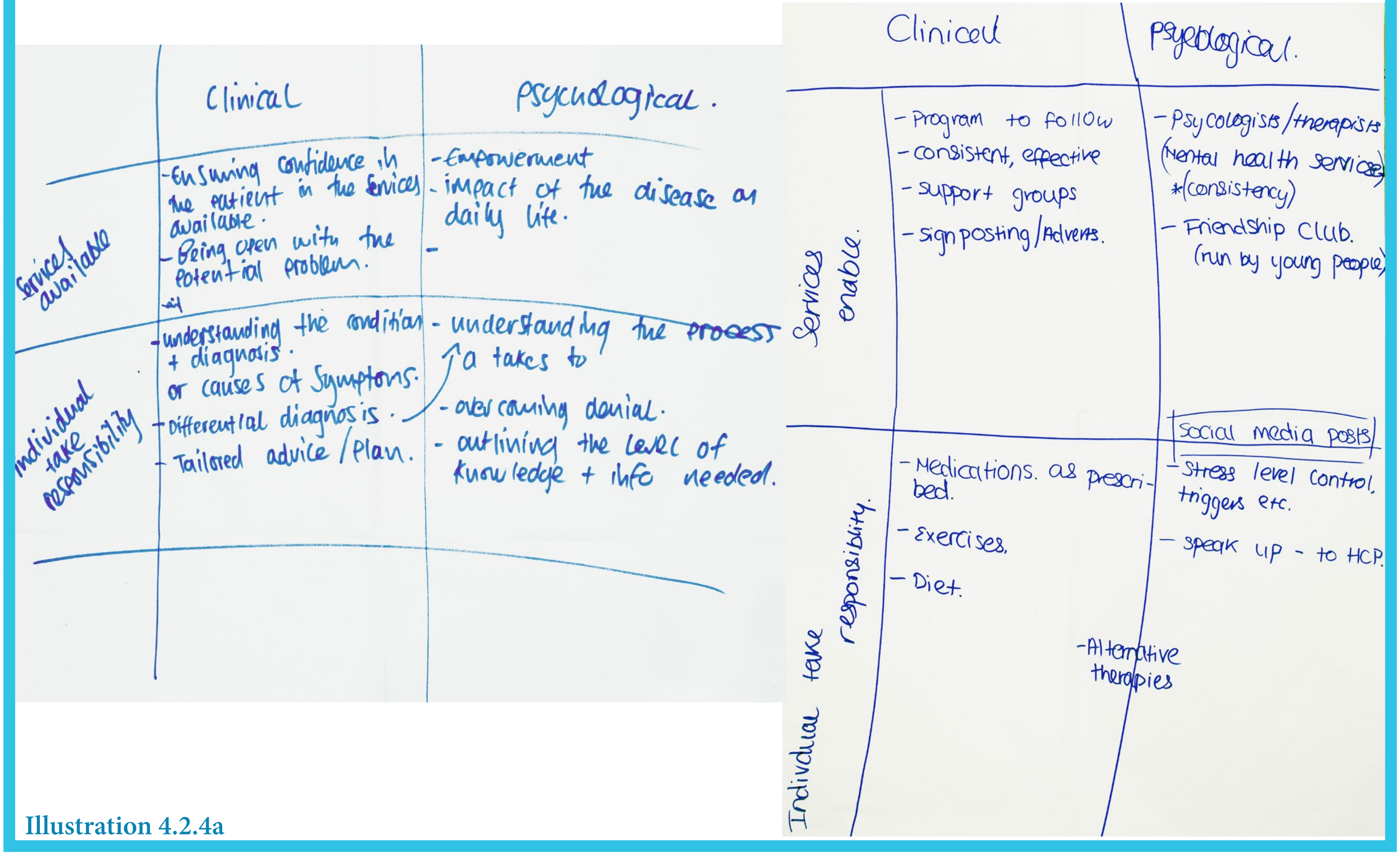
Illustration 4.2.3e

4.2.4 Task 4: How do we Commission for Self-Care?

Taking the issues that were raised during the previous two tasks, participants were asked to think about the kinds of services that are needed to help young adults manage their health. They were asked to discuss the following question:

What types of services do we need to commission?

4.2.4 Task 4: How do we Commission for Self-Care?

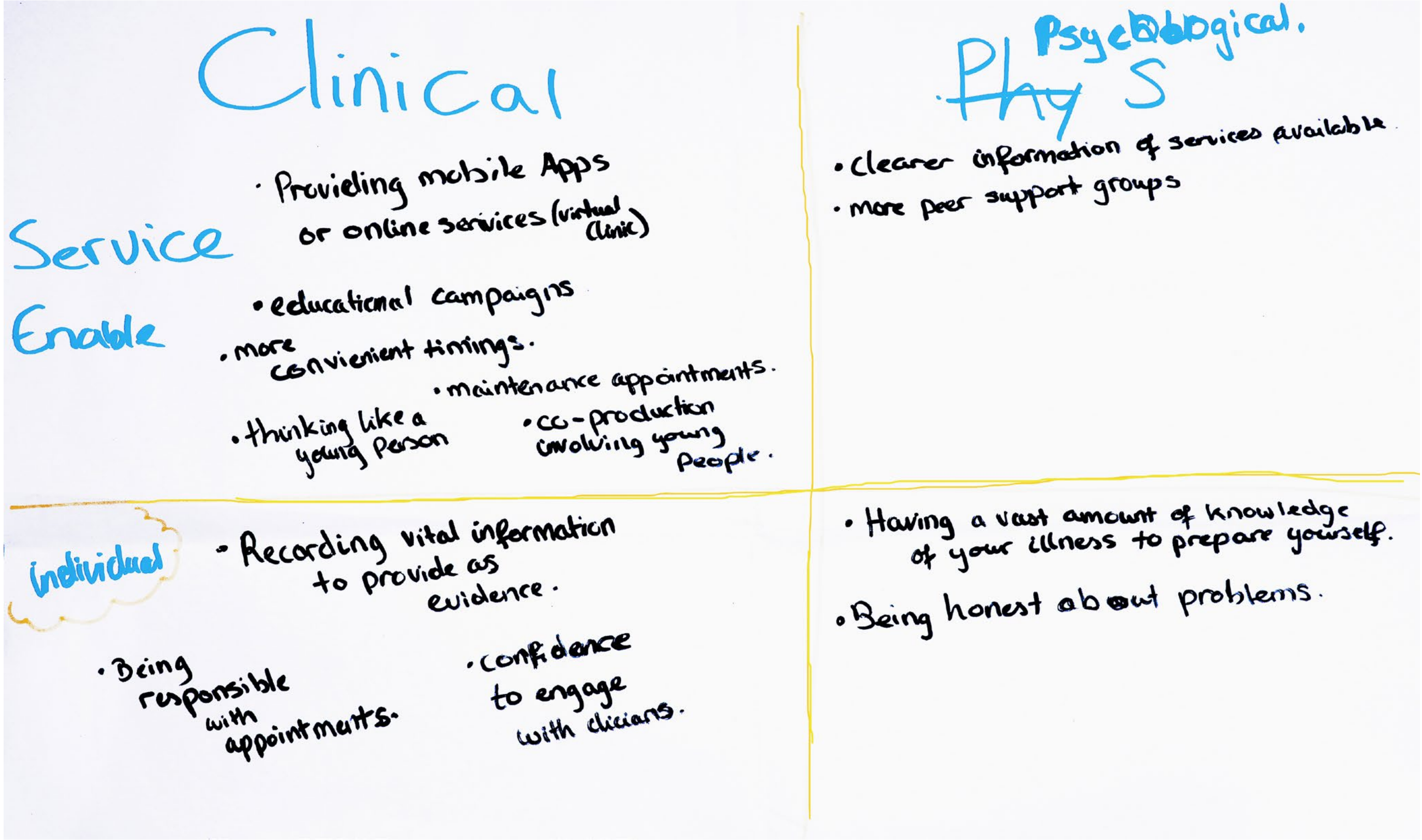


	Clinical	Psychological.
Services available	-Ensuring confidence in the patient in the services available. -Being open with the potential problem.	-Empowerment -impact of the disease on daily life. -
individual take responsibility	-understanding the condition + diagnosis. or causes of Symptoms. -Differential diagnosis. -Tailored advice / Plan.	- understanding the process a takes to -overcoming denial. - outlining the level of knowledge + info needed.

	Clinical	Psychological.
Services enable.	-Program to follow -consistent, effective -support groups -signposting/Adverts.	-Psycologists/therapists (Mental health services) *(consistency) -Friendship Club. (run by young people)
Individual take responsibility.	-Medications. as prescribed. -Exercises. -Diet. -Alternative therapies	Social media posts -Stress level control, triggers etc. -speak up - to HCP.

Illustration 4.2.4a

4.2.4 Task 4: How do we Commission for Self-Care?



Clinical

Service
Enable

- Providing mobile Apps or online services (virtual clinic)
- educational campaigns
- more convienient timings.
- maintenance appointments.
- thinking like a young person
- co-production involving young people.

Psychological.
~~Phy~~ S

- Clearer information of services available.
- more peer support groups

individual

- Recording vital information to provide as evidence.
- Being responsible with appointments.
- confidence to engage with clicians.

- Having a vast amount of knowledge of your illness to prepare yourself.
- Being honest about problems.

Illustration 4.2.4b

4.2.4 Task 4: How do we Commission for Self-Care?

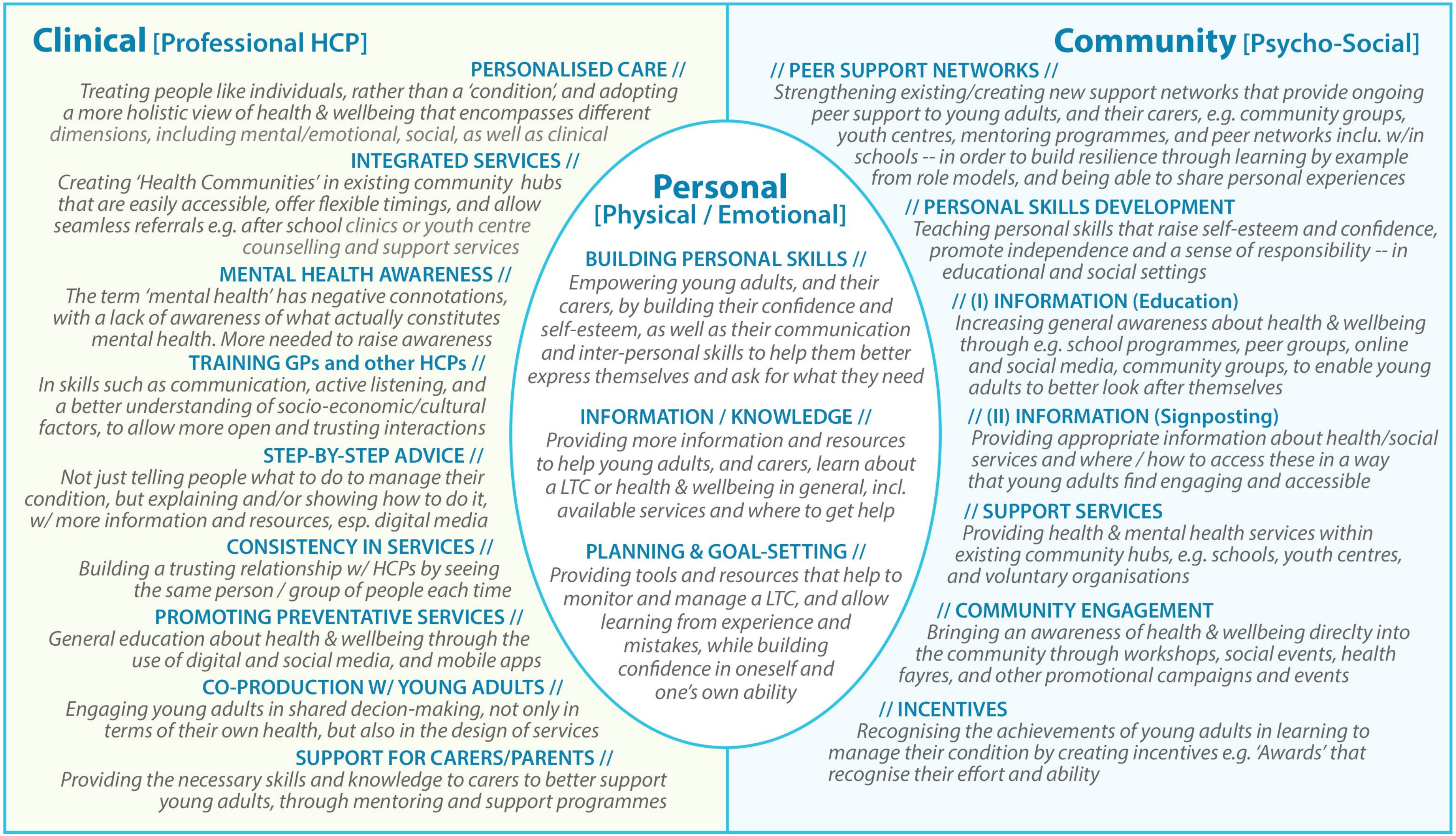
In the final session participants were asked to consider how some of the issues that had been raised earlier (in tasks (ii) ad (iii)), could be addressed through more appropriate commissioning of services. In other words, what would these services look like?

Interestingly, the feedback placed a greater emphasis on making improvements to the way in which existing services were conceptualised, designed and delivered — rather than calling for entirely new services (that were previously unavailable).

The majority of the recommendations called for qualitative improvements to existing service delivery as well as additional support to people in their existing roles. This includes, for example, training for GPs and other HCPs to enable them to better communicate with patients in general, and young adults in particular; more integrated and streamlined services to minimise delays and allow efficient referrals from one service to another; more integration between health and social care services; building the capacity of existing peer support networks; and, strengthening relationships between young people and 'adults' (across all contexts) through mutual respect and trust, with a greater emphasis on joint decision-making.

All the participants agreed that there was currently a gap in available information and resources — whether these were to highlight existing services and where to go for support, or, to help young adults learn about a specific LTC or health in general, so they were better able to look after themselves.

4.2.4 SUMMARY of Feedback from Task 4: How do we Commission for Self-Care?



Clinical [Professional HCP]

PERSONALISED CARE //
Treating people like individuals, rather than a 'condition', and adopting a more holistic view of health & wellbeing that encompasses different dimensions, including mental/emotional, social, as well as clinical

INTEGRATED SERVICES //
Creating 'Health Communities' in existing community hubs that are easily accessible, offer flexible timings, and allow seamless referrals e.g. after school clinics or youth centre counselling and support services

MENTAL HEALTH AWARENESS //
The term 'mental health' has negative connotations, with a lack of awareness of what actually constitutes mental health. More needed to raise awareness

TRAINING GPs and other HCPs //
In skills such as communication, active listening, and a better understanding of socio-economic/cultural factors, to allow more open and trusting interactions

STEP-BY-STEP ADVICE //
Not just telling people what to do to manage their condition, but explaining and/or showing how to do it, w/ more information and resources, esp. digital media

CONSISTENCY IN SERVICES //
Building a trusting relationship w/ HCPs by seeing the same person / group of people each time

PROMOTING PREVENTATIVE SERVICES //
General education about health & wellbeing through the use of digital and social media, and mobile apps

CO-PRODUCTION W/ YOUNG ADULTS //
Engaging young adults in shared decion-making, not only in terms of their own health, but also in the design of services

SUPPORT FOR CARERS/PARENTS //
Providing the necessary skills and knowledge to carers to better support young adults, through mentoring and support programmes

Personal [Physical / Emotional]

BUILDING PERSONAL SKILLS //
Empowering young adults, and their carers, by building their confidence and self-esteem, as well as their communication and inter-personal skills to help them better express themselves and ask for what they need

INFORMATION / KNOWLEDGE //
Providing more information and resources to help young adults, and carers, learn about a LTC or health & wellbeing in general, incl. available services and where to get help

PLANNING & GOAL-SETTING //
Providing tools and resources that help to monitor and manage a LTC, and allow learning from experience and mistakes, while building confidence in oneself and one's own ability

Community [Psycho-Social]

// PEER SUPPORT NETWORKS //
Strengthening existing/creating new support networks that provide ongoing peer support to young adults, and their carers, e.g. community groups, youth centres, mentoring programmes, and peer networks inclu. w/in schools -- in order to build resilience through learning by example from role models, and being able to share personal experiences

// PERSONAL SKILLS DEVELOPMENT
Teaching personal skills that raise self-esteem and confidence, promote independence and a sense of responsibility -- in educational and social settings

// (I) INFORMATION (Education)
Increasing general awareness about health & wellbeing through e.g. school programmes, peer groups, online and social media, community groups, to enable young adults to better look after themselves

// (II) INFORMATION (Signposting)
Providing appropriate information about health/social services and where / how to access these in a way that young adults find engaging and accessible

// SUPPORT SERVICES
Providing health & mental health services within existing community hubs, e.g. schools, youth centres, and voluntary organisations

// COMMUNITY ENGAGEMENT
Bringing an awareness of health & wellbeing direclty into the community through workshops, social events, health fayres, and other promotional campaigns and events

// INCENTIVES
Recognising the achievements of young adults in learning to manage their condition by creating incentives e.g. 'Awards' that recognise their effort and ability

Illustration 4.2.4c

4.3 Workshop Outcomes

The engagement workshops proved to be successful on many different levels; not only did they result in concrete recommendations and invaluable insights, they also demonstrated that engaging young people in a process of co-production and shared decision-making was, in itself, a successful endeavour.

Many of the young participants had never before been given a platform on which to express themselves, share concerns, and make suggestions. Based on their (post-workshop) feedback, they felt that their voices were heard and they had been able to influence the programme agenda.

Being a pan-London initiative, the young adults who took part in the workshops represented a diverse demographic — from high school students in South London, to young volunteers overcoming physical disability in West London, and teenagers from a disadvantaged community in inner city London. The workshop participants were made up of both those who had a LTC or other health condition, or were carers for family members with a LTC — and those who had no significant health concerns at this time. Some of the participants were actively dealing with social issues, unemployment and homelessness, or were otherwise in transitional periods of life.

Despite the differences in background, age, and personal (health/social) concerns — the young adults engaged in the process, collaborated with each other, and with other professionals and stakeholders, and were proactive in voicing their opinions, sharing their experiences, and making recommendations. For many of them, this was the first time they had sat down with 'adults' in an open and equal exchange about the challenges they faced and what could be done to address them. As one participant noted: "*It was good to have the diversity and age range. We never get a chance to have a debate with a 60 year old.*"

There were three primary outcomes from the engagement events, which are summarised below:

(i) The feedback from the workshops demonstrated that we need to rethink our current definition of self-care. A more expansive and holistic approach is needed for 'health and wellbeing' in general, and 'self-care' in particular. A different

4.3 Workshop Outcomes ... cont'd

perspective, based on this new understanding, will, therefore, necessitate a more holistic and integrated approach to commissioning services.

(ii) Almost all the feedback resonated with, thereby validating, the various issues and themes that were highlighted during the *Evidence Review* and the Call for Evidence.

(iii) The success of the engagement process set an important precedent, and in so doing, has formed the basis for an engagement framework, or methodology, that can be further articulated and developed for use in other similar programmes in the future.

The combined feedback from the Evidence Review, Call for Evidence, and Engagement Workshops, are developed into a series of recommendations in the next chapter.

4.4 List of Participants

South London // Dunraven School

// Co-Facilitators: Saron Dawit / Qubi Jarrett / Grace McDermott / Alessia Mobile / Omoyele Rose / Raymond Tavener

// Event Co-ordinators: Mohamed Abdallah / Philip Dyas / Ruth Mason

West London // Hillingdon Association of Voluntary Services (HAVS) &

// Co-Facilitators: Nuelia Allson / Darryl Ashcross / Jake Austen / Natalie Bishop / Chood Boyce / Sean Gallagher / Sagar Koria / William O'Conner / Nimesh Pattani / Taz Virdee

// Event Co-ordinators: Rob Burton

North-East London // N-E London Local Pharmaceutical Committee (NELLPC)

// Co-Facilitators: Tahmid Alam / H. Aziz / Betty Dodoo / Shandies Rose / Sema Thasnim / Lucy Toole / Jamil Wallace /

// Event Co-ordinators: Natalia Gomez / Hemant Patel

Central London // King's Cross Brunswick Neighbourhood Association (KCBNA)

// Co-Facilitators: Hamza Ahmed / Hussein Ahmed / Aaliyah Begum / Helena Begum / Taslima Begum / Elmi Dahir / Md Abdul Halim / Enamul Hasan / Ifat Hussain / Tahmin Hussain / Kalad Islam / Amin Jama / Waleed Jama / Sayem Jaman / Shenaz Kaji / Arif Kaif / Khalif Mahamud / Adam Meragan / Emon Miah / Fahim Miah / Remon Miah / Shaon Miah / Sayeem Miah / Samuel Mohammed / Guled Abdi Nasir / Guled Shire / Jahid Uddin

// Event Co-ordinators: Abdul Hai / Harun Kaji / Muhammod Shofi

PART II

BUILDING AN EVIDENCE BASE

CHAPTER 5 / SUMMARY OF OUTCOMES

5.1 Building on the House of Care Model
5.2 Connecting Policy and Grassroots Engagement
5.3 Young Adults & Self-Care

5.1 Building on the House of Care Model

The Made in London project was initiated with the aim of creating a framework for embedding self-care in the commissioning of services for young adults in London. In order to define what this self-care framework would look like, and understand how it would work in practice — the Senate agreed that the project needed to be underpinned by a process-oriented approach, one that was:

// Evidence-based — developing solutions based on extensive research and engagement at the organisational, community, and individual levels;

// Collaborative — actively involving young adults in a process of joint decision-making and co-production;

// Asset-based — building the skills of young adults to engage effectively in identifying needs and making recommendations; and,

// Continuous & Iterative — responsive to feedback and flexible enough to accommodate new information and insights at each level of engagement.

Based on this approach, the scope of work included the following four phases:

(i) Evidence Review;

(ii) Call for Evidence;

(iii) Engagement Workshops; and,

(iv) Recommendations & Review

The starting point for the project was the Evidence Review, which framed the overall policy and organisational context and formed the foundation for the subsequent work.

The following three phases were defined by different types and levels of engagement. The Call for Evidence invited different service providers and community groups across London to share their experiences of self-care support, highlight challenges, and make recommendations in response to a series of consultation questions. The Engagement Workshops, and the subsequent Review session, created a platform for young adults to take the lead in running the events and driving the programme agenda by ensuring that the voices of all the young people were heard and that the eventual recommendations did, indeed, reflect their feedback.

Interestingly — though, perhaps, not surprisingly — the evidence and insights generated during each phase of the project resonated with and validated the evidence from each of the other phases.

5.1 Building on the House of Care Model ... cont'd

Data gathered during the Evidence Review supported the 'House of Care' as a holistic and sustainable model as a basis for developing a self-care framework as shown in Illustration 5.1a.

In addition, the Health Foundation's three-tiered model for transformation, (based on the House of Care), suggests that changes to self-care support services need to happen in parallel, they cannot simply focus on individual, segmented areas of improvement but need to consider how they all fit together and complement each other. Illustration 5.1b shows the three primary areas highlighted by the Health Foundation: person-centred care, training for HCPs, and organisational processes that support self-care.

Feedback from both the Call for Evidence and the Engagement Workshops supported using the House of Care model and the three-tiered model for transformation as the basis of building a self-care framework for young adults. The key points from these stages, set out below, reflect this approach:

1/ The importance of involving patients and the public in the design and development of services and the production of educational and support tools;
2/ The need for services that are more patient-focused and holistic in their approach to treatment and support;
3/ The need for education and training for professionals and patients in order to change the culture of organisations and enable adoption of self-care programmes; and,

4/ Multi-professional collaborative working that looks beyond the disease/condition and crosses the commissioner/provider/patient boundaries.

[summary of feedback from the Call for Evidence]

The feedback from these phases also reinforced guidance published by NHS England (2015) to support commissioners and practitioners in planning services for people with LTCs, as highlighted in the next section 5.2.

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5.1 Building on the House of Care Model ... cont'd

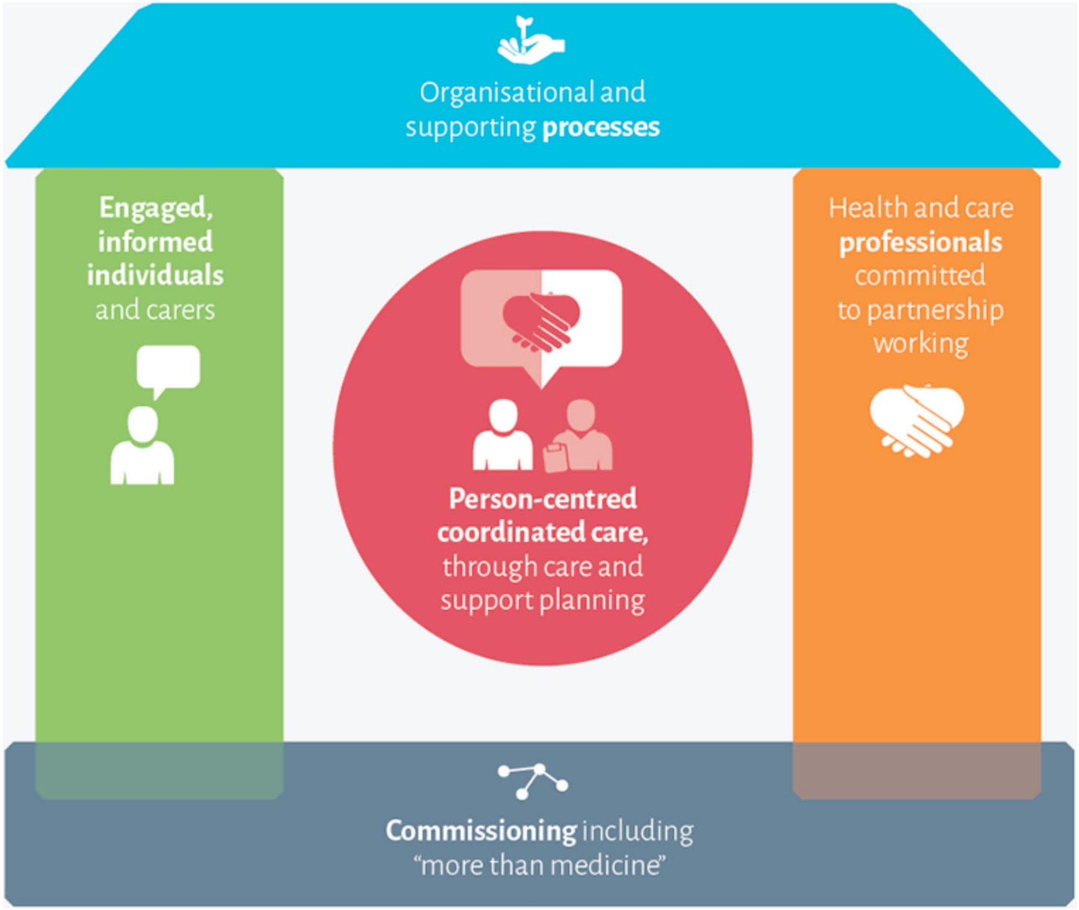
Illustration 5.1a /
Key recommendations from the Call for Evidence mapped onto the House of Care

Funded transition specific therapy posts

Shared facility for health and social care services

Flexible, responsive and integrated approach

Joint pathways of care



Social media / new techs to create supportive virtual communities

Provision of information at the right time and right format

Use of social media / new techs to improve self-care behaviours

Easy access into the service including self-referral

Empower people to self-manage

Self-management assessment tools from early age (at least 12 yrs)

Co-design information and education resources

Ongoing support through transitional periods

Individualised approach to goal setting and treatment

Holistic framework that encompasses 'health & wellbeing'

Multi-disciplinary engagement

Communication between partners to enable seamless transition of care

Active participation of GPs in care of patients from an early age

Senior buy-in when introducing new models

User involvement in the design of services

Joint commissioning with partner organisations

Fostering partnerships with patients and clinicians

5.1 Building on the House of Care Model ... cont'd

The Health Foundation's three-tiered approach is based on the 'House of Care" and offers a framework for holistic self-care transformation. The Health Foundation suggest that changes to self-care support services need to happen in parallel – they cannot simply focus on one area of improvement whilst developing the systems and workforce to support this change.

Illustration 5.1b

1. Commissioning Evidence-Based self-care
Giving people with long term conditions the skills, confidence and support to self manage.

2. Clinician Training
Helping clinicians to develop the skills, knowledge and attitude to support and motivate people with long term conditions.

3. Changing health systems
So that they encourage and facilitate self-care.

5.2 Connecting Policy and Grassroots Engagement

NHS England England Guidance
to support commissioners and practitioners
in planning services for people with LTCs

Ensure that commissioning reflects the needs of individuals, and commission appropriate person-centred services that promote and embed personalised care and support planning;

Promote partnership and collaboration in local health populations to implement a whole system approach;

Commission a range of support services for self-management to supplement traditional services and to ensure a 'more than medicine' approach. This could include structured education programmes, community activities and peer support networks;

Ensure that support is in place to provide people with timely, appropriate and accessible information to enable them to make an informed contribution to discussions regarding their condition, care and support;

Promote the development of clinical environments that encourage shared decision making approaches and ensure support systems are in place to support patients who are less able to embrace this approach;

Promote the development of the workforce to have the skills and competencies to work in this way;

Ensure a robust local measurement system is in place to inform and support improvement.

Feedback from *Made in London* Engagement Workshops
Task 4: How do we commission for self-care?

// PERSONALISED CARE
Treating people like individuals, rather than a 'condition', and adopting a more holistic view of health & wellbeing that encompasses different dimensions, including mental/emotional, social, as well as clinical

// INTEGRATED SERVICES
Creating 'Health Communities' in existing community hubs that are easily accessible, offer flexible timings, and allow seamless referrals e.g. after school clinics or youth centre counselling and support services

// STEP-BY-STEP ADVICE
Not just telling people what to do to manage their condition, but explaining and/ or showing how to do it, w/ more information and resources, esp. digital media

// PEER SUPPORT NETWORKS
Strengthening existing/creating new support networks that provide ongoing peer support to young adults, and their carers, e.g. community groups, youth centres, mentoring programmes, and peer networks inclu. w/in schools

// (I) INFORMATION (Education)
Increasing general awareness about health & wellbeing through e.g. school programmes, peer groups, online and social media, and community groups

// (II) INFORMATION (Signposting)
Providing appropriate information about health/social services and where / how to access these in a way that young adults find engaging and accessible

// CO-PRODUCTION W/ YOUNG ADULTS
Engaging young adults in shared decion-making, not only in terms of their own health, but also in the design of services

// TRAINING GPs and other HCPs
In skills such as communication, active listening, and a better understanding of socio-economic/cultural factors, to allow more open and trusting interactions

5.3 Young Adults & Self-Care

The senate identified young adults as a group that was currently underserved in terms of self-care provision. The feedback from the project reinforced this view and highlighted two key issues: not only were improved services required to meet the current needs of young adults and carers, they were also required as a pre-emptive measure to counter poor health outcomes in the future, as a result of conditions originating in adolescence.

The Evidence Review identified Adolescence as a period when significant physical, psychological, and behavioural changes occur and when people develop many of the habits, behavioural patterns and relationships they will carry into their adult lives, for example:

// Smoking in the UK increases from a population prevalence of 1% at age 11 years to around 20% at 15 years. Nearly 90% of lifetime smoking is initiated between the ages of 10 and 20 years in the UK

// About 80% of lifetime alcohol or cannabis use is initiated under 20

// Five of the 10 key risk factors for adult disease burden identified in the WHO Global Burden of Disease Study (tobacco, physical activity, overweight, unsafe sex and alcohol use) are problems that are usually initiated or heavily shaped in adolescence.

// Nearly two-thirds of premature deaths and one-third of the total disease burden in adults are associated with conditions or behaviours that began in their youth, including: tobacco use, a lack of physical activity, unprotected sex or exposure to violence.

// Morbidity due to disability and long-term conditions is higher among adolescents than children.

// About 75% of lifetime mental health disorders have their onset before 18 years of age, with the peak onset of most conditions being from 8 to 15 years. About 10% of adolescents suffer from a mental health problem at any one time.

When viewed alongside the population profile for London — where 1 in 4 people are children and teenagers under 20 years — this data emphasises the need to develop effective self-care programmes for young adults in general, and in London, in particular.

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PART III / RECOMMENDATIONS

PART III
RECOMMENDATIONS

CHAPTER 6 / DEVELOPING A SELF-CARE FRAMEWORK

6.1 Commissioning for Self-Care

The combined outcomes from the Made in London project — across the different project phases — support the 'House of Care' model as a basis for developing a self-care framework for young adults. They reinforced the importance of developing the different dimensions of care as highlighted in the model, including "Person-centred co-ordinated care", "Health and care professionals committed to partnership working", and, 'Commissioning including 'more than medicine,' (see illustration 6.1a).

While the outcomes support this basic model, they also highlighted the need for a framework that is still broader in scope, multi-disciplinary and relevant in different contexts (not only clinical).

Evidence collected during the project highlighted recurrent issues, themes, and recommendations. The engagement events, in particular, demonstrated a general consensus amongst the participants, (beyond individual concerns and irrespective of demographic), on the areas of service design and delivery that need to be prioritised.

Importantly, the feedback emphasised a qualitative improvement to existing services and additional support to existing communities — rather than calling for new services (that are currently unavailable). The recommendations encompassed a broad range of improvements, from behaviour change at an individual level to more relevant commissioning at an organisational level.

These recommendations have been distilled into 'ten key points for commissioners' (see illustration 6.2a), and fall under the following sub-categories (based on the House of Care) —

// Approach

// Engaged, Informed Individuals & Carers

// Person-Centred Care

// Health & Care Professionals Committed to Partnership Working

// Organisational & Supporting Processes

—

6.1 Commissioning for Self-Care ... cont'd

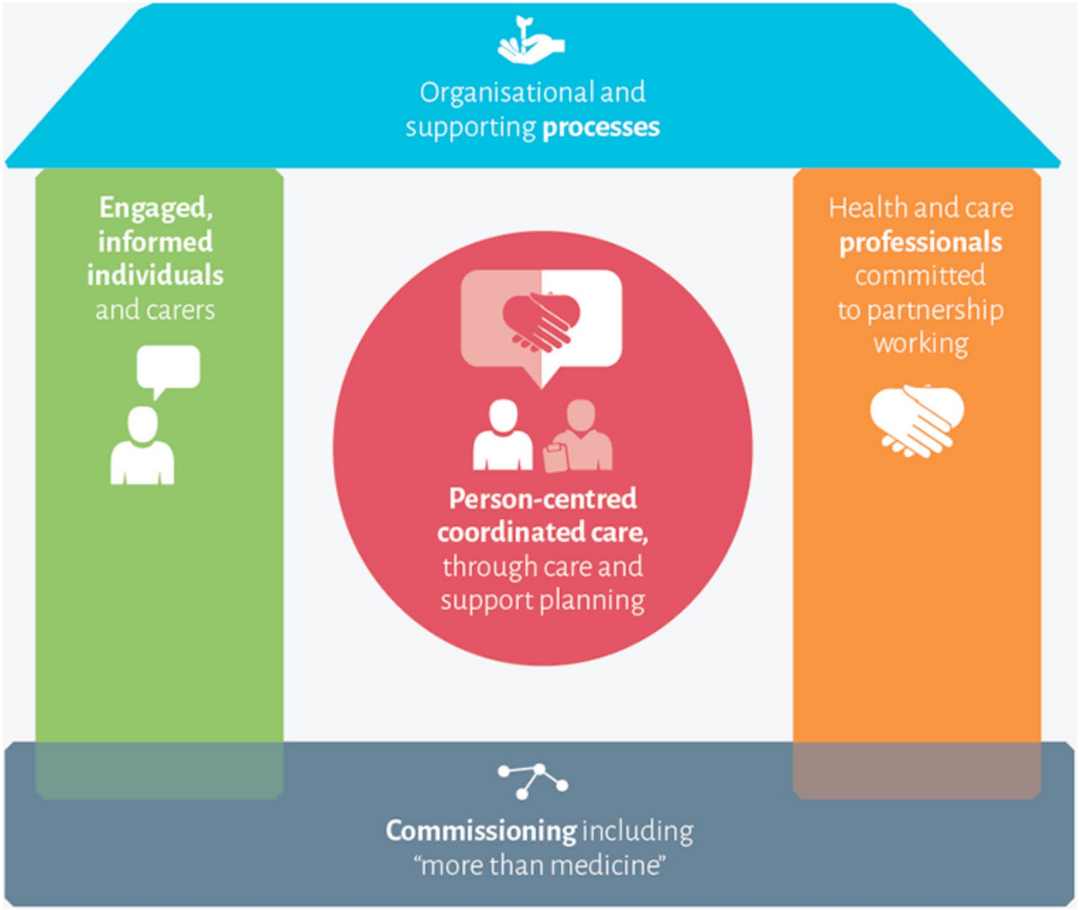
Illustration 6.1a /
Key recommendations from the Call for Evidence mapped onto the House of Care

Funded transition specific therapy posts

Shared facility for health and social care services

Flexible, responsive and integrated approach

Joint pathways of care



Social media / new techs to create supportive virtual communities

Provision of information at the right time and right format

Use of social media / new techs to improve self-care behaviours

Easy access into the service including self-referral

Empower people to self-manage

Self-management assessment tools from early age (at least 12 yrs)

Co-design information and education resources

Ongoing support through transitional periods

Individualised approach to goal setting and treatment

Holistic framework that encompasses 'health & wellbeing'

Multi-disciplinary engagement

Communication between partners to enable seamless transition of care

Active participation of GPs in care of patients from an early age

Senior buy-in when introducing new models

User involvement in the design of services

Joint commissioning with partner organisations

Fostering partnerships with patients and clinicians

6.2 10 Key Points for Commissioners

Illustration 6.2a

APPROACH

1/ Utitlise a Process-Oriented Approach
to commissioning services — one that is:
(i) **Evidence-based** / (ii) **Collaborative**
(iii) **Asset-based** / (iv) **Continuous & Iterative**

ENGAGED, INFORMED INDIVIDUALS & CARERS

2/ Co-production and Shared Decision-making
Involving patients and the public in the design and development of services and the production of educational and support tools and systems.

3/ Supporting existing/new peer networks
Creating 'safe spaces' in the community where young adults can share their experiences.

PERSON-CENTRED CARE

Delivering services that are more person-centred in their approach to treatment and support, incl:

4/ Supporting a holistic view of Health & Wellbeing

5/ Personalising Care

6/ Creating Welcoming & User-friendly Environments

HEALTH & CARE PROFESSIONALS COMMITTED TO PARTNERSHIP WORKING

Education and training for professionals in order to support the development and adoption of self-care programmes, in particular:

7/ Embedding a 'Cultural Change' amongst Professionals and within organisations

8/ Building Capacity & Training of Frontline Staff

And, multi-professional collaborative working that supports the integration of health and social care, and transcends the commissioner/provider/patient boundaries, through:

9/ Creating 'Health Communities'

ORGANISATIONAL & SUPPORTING PROCESSES

10/ Enabling 'Systems Thinking'
Create a culture that fosters systems thinking and provides systems leadership to facilitate the creation of multi-disciplinary, integrated frameworks for commissioning services. This includes supporting innovation that actively encourages and evaluates new ideas and projects to build capacity.

MORE EFFECTIVE COMMUNICATION / INFORMATION / KNOWLEDGE ACROSS ALL AREAS

6.2 10 Key Points for Commissioners

APPROACH

1/ Utitlise a Process-Oriented Approach
to commissioning services — one that is:

(i) Collaborative:
Bringing clinicians, commissioners, staff, patients, service users, carers and the community together as equal partners to develop standards for good practice and agree high impact initiatives for recommendation to commissioners;

(ii) Evidence-based:
Developing and promoting evidence-based solutions that build on existing evidence and good practice, as well as drawing on the experiential knowledge of service users, and professionals, through community wide engagement;

(iii) Asset-based:
Developing the capacity of patients, service users and the community to engage effectively in identifying needs, the planning, development, and delivery of services, and making recommendations to commissioners;

(iv) Continuous and iterative:
Engaging to build and refine sustainable models for local and pan-London commissioning that reflect the needs and aspirations of service users and frontline staff, including collaboratively reviewing, and agreeing, outputs and recommendations.

ENGAGED, INFORMED INDIVIDUALS & CARERS

2/ Co-Production and Shared-Decision Making

Engaging local people in the design and development of services and support tools, is central to providing healthcare that is contextually relevant, cost-effective, and sustainable. Only by understanding what a local community needs, can services be designed and delivered accordingly. This is in line with the participatory healthcare framework set out in The Health and Social Care Act 2012, which requires commissioners and CCGs to enable:

— Patients and carers to participate in planning, managing and making decisions about their care and treatment, through the services they commission;

— The effective participation of the public in the commissioning process itself, so that services provided reflect the needs of local people.

Starting with the people you are commissioning for involves:

6.2 10 Key Points for Commissioners ... cont'd

(i) Engaging service users and professionals with experience of public and patient engagement, at the earliest possible stage;

(ii) Having them participate through the course of the project and across all the phases, including: identifying gaps and setting the programme agenda, project design and development, initiating wider engagement, validation and sign-off, and, implementation and monitoring;

(iii) Identifying the support needs of people and providing that support to enable them to successfully participate in engagement.

Only by actively engaging with the communities they are commissioning for and the providers of those services, can commissioning organisations ensure the relevance and effectiveness of a programme.

3/ Supporting Peer Networks

The importance of peer support and mentoring was emphasised across all the project phases, and was a key theme during the engagement workshops. Young adults felt this was an invaluable means of providing necessary support, whether to help people manage a LTC, or to help them deal with personal and social issues. They identified the following three points as necessary components of successful peer support:

(i) Having someone you can relate to (in terms of age and background), who is going through the same experience provide encouragement, offer advice, and share their experiences. Equally important, is the ability to provide mentoring and support to others by sharing your own personal experiences — thereby establishing a two-way support system of learning and sharing;

(ii) Having someone there with you, who is going through the same/similar experience — go through it at the same time as you. This way, it's possible to 'bounce ideas off each other' and gain encouragement knowing that someone else is going through the same thing, at the same time;

(iii) Having a 'safe space' in the community where young adults can feel valued, and a main point of contact — whether a teacher / mentor / youth worker / friend — in whom to confide and share concerns.

PERSON-CENTRED CARE

Delivering services that are more person-centred and holistic in their approach to treatment and support.

6.2 10 Key Points for Commissioners ... cont'd

4/ Supporting a Holistic View of Health & Wellbeing

Feedback from the Call for Evidence and Engagement Workshops reinforced the view that care is currently fragmented and needs to take a more holistic approach — one that is based on a far more expansive understanding of 'health and wellbeing' that encompasses the many different dimensions of health, in addition to just the physical.

Workshop participants also highlighted the current gap in mental health awareness amongst young adults. They emphasised the importance of good emotional/mental health and its impact on physical wellbeing, educational achievement, and ability to work.

The workshop discussions around what self-care means, and the co-production of a new definition of self-care — helped to articulate a more expansive understanding of 'health and wellbeing' and demonstrated that it went even further than encompassing mental/emotional health, to also include personal skills, education, employment, and social support, (see 6.4: Visualising New Models of Self-Care).

5/ Personalising Care

The workshops highlighted the fact that a 'one size fits all' does not work, and that services need to be 'patient-focused' and responsive at an individual level. Many of the participants criticised HCPs for *'treating a condition and not the individual'.*

Moreover, they felt that GPs, in particular, *'lacked empathy; didn't spend enough time with patients; didn't show enough respect to young people; didn't communicate the issues in a way that young people could understand; told them what to do but not how; and, tended to focus on the negative aspects of a LTC and/or patient behaviour, without acknowledging the positive steps that had been taken'.*

For the majority, visiting a GP was seen as a stressful experience, both in terms of the overall [perceived poor] quality of service and interaction, and the physical environments which were described as 'cold and unfriendly'.

The workshops also suggested that a more personalised approach would have to be responsive to changing demographics across London as a whole: age, income and employment, education, social/cultural/religious norms, and other factors, to ensure appropriateness of services provided.

6.2 10 Key Points for Commissioners ... cont'd

Providing Step-by-Step Advice

> *"We need ways to deliver care in a more patient-focused way. This requires an individualised approach to goal-setting and treatment planning." [Feedback from Evidence Review]*

> *"You only see the GP when there is a problem. There is no way of finding out how I am doing and if I am on the right track [the rest of the time]."* [Feedback from Workshops]

As well as communicating a clear understanding of the health condition, HCPs need to develop step-by-step guidelines and resources to help patients self-manage. While such resources need to be conceptualised and delivered in the most appropriate format — (whether mobiles apps, websites, games, booklets, etc.) — there is definitely the need to provide engaging and interactive ways for people to understand, manage, and monitor their condition, as well as share lessons learned.

Ensuring Consistent Care

The young adults who took part in the workshops felt that some measure of consistency of care was very important — both in terms of ensuring consistent quality of services provided, as well as consistency in staffing. They felt that being able to see the same HCP / group of HCPs would help to build trust and develop a relationship over time.

6/ Creating Welcoming and User-friendly Environments

Existing healthcare environments were criticised during the workshops for being 'cold and unfriendly'. This includes all the different spaces that a patient has to pass through during a visit, from entrances and reception areas, to consultation offices and examination rooms. Designing more welcoming and user-friendly environments would not only improve accessibility in general, but would also contribute to the 'cultural change' highlighted above. Moving services from existing healthcare locations into community settings would also help to facilitate a change in the patient professional dynamic that currently exists.

HEALTH & CARE PROFESSIONALS COMMITTED TO PARTNERSHIP WORKING

Education and training for professionals in order to support the adoption of self-care programmes, in particular:

6.2 10 Key Points for Commissioners ... cont'd

7/ Embedding a 'Cultural Change' amongst Professionals and within Organisations

All the evidence gathered, from each phase of the project, called for a 'cultural change' amongst service providers. While the points highlighted above would act as a catalyst for such a change, a more direct approach is still needed in the form of training for GPs / HCPs and other professionals, in interpersonal skills and communication techniques.

The following quotes from young adults highlight the many challenges that currently exist:

"They [adults] don't take us seriously."

"Clinicians need to treat me like a person. Sometimes they lack sensitivity in how they talk to us [young adults] about our health matters."

"I had to stop my mum coming with me for my appointments because the doctor would ignore me completely and just talk to her. I was 16 and he would still ask her questions like 'What does she eat?' or 'What did she do.' "

"I was in such shock when I first heard I had diabetes. Even my parents were totally shocked ... We didn't know where to go, who to speak to, what to do. The doctors and nurses just told us the diagnosis and left us on our own. I feel there should have been support for both me and my parents."

"Clinicians tend to give you all the negatives about the condition which makes us feel really down. It is always about what is wrong and what is not working."
[feedback from Engagement Workshops]

People need to feel that 'someone is actually listening' to them, and this can be supported through training in 'active listening', including being attentive, greeting people, making eye contact, and paying attention to body language. Building interpersonal skills and training in communication techniques would, potentially, transform the relationship between the patient/young adult and GP/HCP, by fostering trusting interactions, honest communication, and respect for each other's roles, abilities, motivations, and goals.

8/ Building Capacity & Training of Frontline Staff

In order to support a more holistic approach to providing services, frontline staff need the knowledge, skills, and resources to enable them to provide care within this framework. They would need training in a 'more than medicine' approach to engagement, treatment, and management.

6.2 10 Key Points for Commissioners ... cont'd

9/ Creating 'Health Communities'

Multi-professional collaborative working that supports the integration of health and social care services, and transcends the commissioner / provider / patient boundaries, through the creation of 'Health Communities'.

The evidence gathered during the project highlighted the importance of working in partnership. This encompasses partnerships not only between service users and HCPs and/or commissioners — but also between and across organisations.

This is especially important in light of a more holistic understanding of health and wellbeing that calls for an increasing integration of services (e.g. healthcare and social and community services). In this context, a collaborative approach becomes necessary; one that emphasises common aims, joint programming, processes, systems, and evaluative functions.

Creating a 'Menu of Services'

Feedback from the workshops suggested that 'self-care' is a process that takes place across a range of different contexts, not just within clinical settings — it 'happens' at home, in schools, youth centres, community groups, and is supported by different local authority service providers.

As such, healthcare services need to be conceptualised and designed alongside other services and/or within non-clinical settings. There is, therefore, a strong case for creating 'health communities' in existing community hubs that provide a range of complementary services in one convenient location.

While the number of existing 'health communities' is still limited, a few case studies from across London, demonstrate the success of the model in practice; these include:

// The Well Centre, in South London, is a 'health and youth centre' that offers healthcare services alongside mental health and youth counselling services at an existing community youth hub, (see 6.4.2 (i)).

// Dunraven School, in Streatham, provides a range of support services to students, including after-school counselling and peer support to bolster emotional wellbeing, helps students manage LTCs within the context of their daily routines, and advises them on available options for vocational training and apprenticeships, (see 6.4.2 (ii)).

6.2 10 Key Points for Commissioners ... cont'd

// The Community Pharmacies, in north-east London, provide integrated care that combines the physical and clinical aspects of health with the psychosocial, including behaviour change techniques and patient empowerment, (see 6.4.2 (iii)).

All of these examples show how health and/or social care services can be integrated into existing community hubs with positive outcomes, such as encouraging access, providing flexible timings, reducing number of hours of missed school or work, convenient access to information and advice, as well as providing a sense of community and social cohesion.

Designing for Transitions

In addition to integrating different types of services (e.g. health and social care) and making them available in one easily accessible community hub — there is also the need to integrate services to provide seamless care for young adults across transitional periods. These transitions from one stage of life to another often highlight personal, health, and social issues simultaneously.

Examples include: expanding existing or creating new services to encompass the transition between paediatric and adult services to ensure consistent care; providing information and guidance on how to integrate the management of a LTC into daily life; and, supporting young adults through periods of unemployment to employment and 'independent living' through personal skills development.

ORGANISATIONAL & SUPPORTING PROCESSES

10/ Enabling 'Systems Thinking'

Create a culture that fosters systems thinking and provides systems leadership to facilitate the creation of multi-disciplinary and integrated frameworks for commissioning services. This includes supporting innovation that actively encourages and evaluates new ideas and projects to build capacity.

The creation of 'Health Communities' listed above (point 9) also falls under this category, as it is predicated on a multi-disciplinary and integrated framework that necessitates working in partnership across and between different organisations.

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6.3 Communication, Information & Knowledge

The term 'information' came up repeatedly during both the Call for Evidence and the Engagement Workshops. What participants meant by 'information' varied depending on context. In some instances, 'information' was used to refer to effective signposting of services, whereas in others, it referred more to education and learning about a LTC.

For clarity, the feedback from the workshops (pertaining to 'information') has been grouped into three distinct, but related, categories, which include Communication, Information, and Knowledge. These are summarised below, within the context of self-care and young adults.

(i) Communication //

Effective interpersonal communication with another, through open, honest dialogue.

Workshop participants admitted they often don't know how to ask for help, or express their feelings. Providing communication skills would help to empower young adults, not only within a healthcare environment, but in everyday life in general. Equally, they felt that HCPs failed to communicate effectively, with a lack of respect conveyed through language, tone, and body language.

(ii) Information //

Providing general information and advice through digital and social media.

With the increasing reliance on digital and social media, particularly amongst young adults, there is a strong case for healthcare providers to use these channels to share information about services in a way that is convenient and flexible and actively engages young adults.

(iii) Knowledge //

Transforming information into 'insight' and knowledge, in a way that leads to a change in attitude and behaviour.

Young adults understood that they often lack the knowledge about their LTC, or health in general, and were, therefore, unable to make the right choices. They identified a need to have more education around self-care — through a combination of educational resources and more structured programmes — to help them better understand their health and make positive changes.

A combination of Communication, Information, and Knowledge is required across all the ten points highlighted above, as well as the ability, on a continuous basis, for young adults and carers to be involved in the design and development of services so they can provide feedback for how services and supporting resources can be improved.

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6.4 Visualising New Models of Self-Care

> *'Rehabilitation focuses not only on the person's health but on helping them live fulfilling lives in terms of education and employment, finances, relationships, psychosocial and physical aspects of daily living. For rehabilitation to be effective, it needs to take place within an holistic framework, necessitating multi-professional engagement and joint-working.'*
> [Call for Evidence/Feedback]

The broad definition of 'self-care' that emerged through the workshops reinforced the view that a traditional 'compartmentalised' approach to service delivery is no longer appropriate or desirable. Instead, it has become necessary to step back and take a wider perspective that encompasses all the different facets that make up self-care. These include not only the physical and mental/emotional dimensions of 'health and wellbeing', but also the social support systems (e.g. through school, community organisations, local authority services), as well as personal skills development, that are needed to live a healthy and balanced life.

6.4.1 Introducing the Self-Care Wheel

Given that 'self-care' often takes place outside traditional clinical settings, healthcare services need to be conceptualised and designed alongside other services and within non-clinical settings.

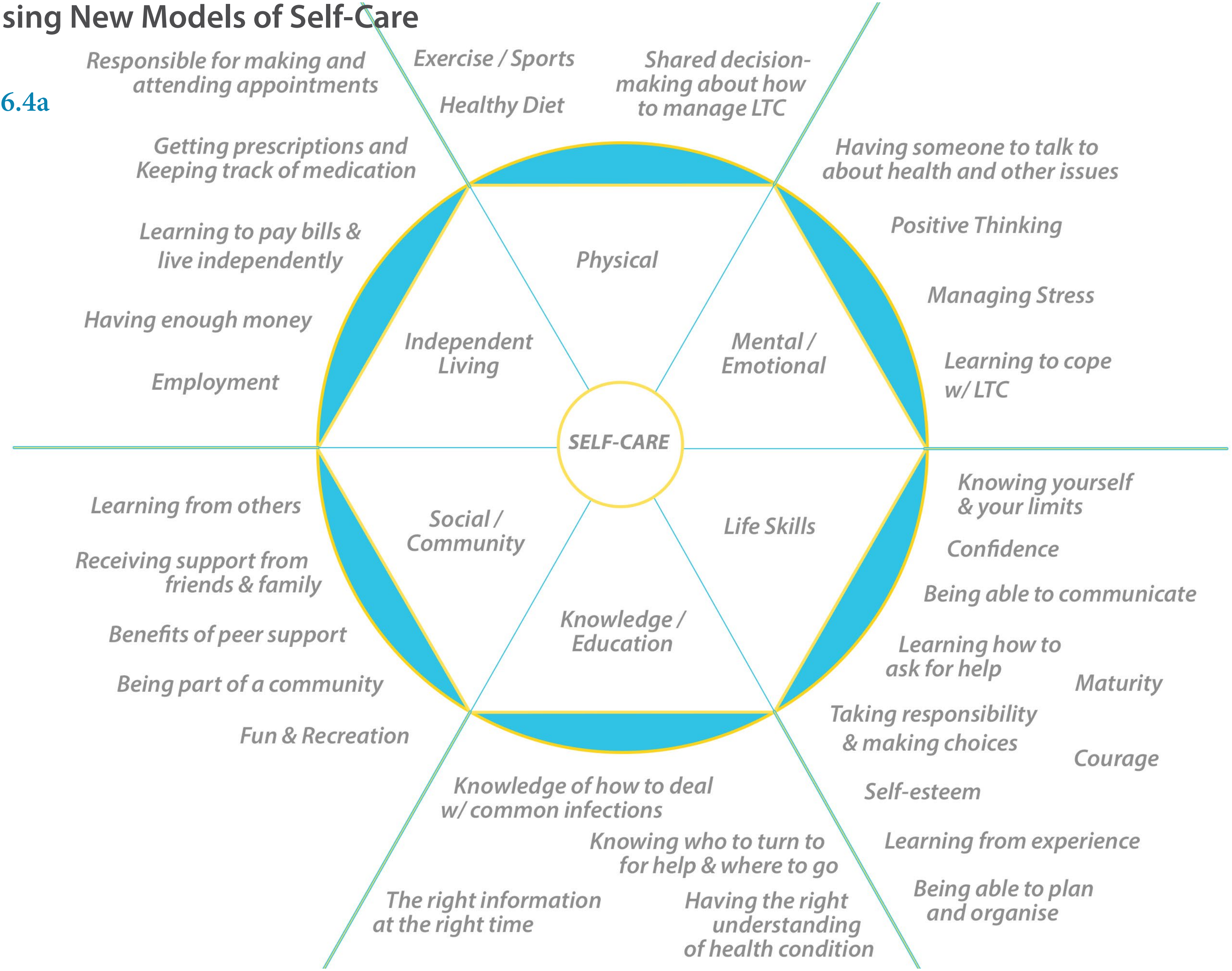
The different dimensions of self-care that were highlighted during the engagement workshops are shown in the following diagram (illustration 6.4a). It includes both quantitative behaviours such as healthy eating and physical activity, and more qualitative 'ways of being', encompassing attitudes, beliefs, and expectations. The diagram also highlights the different contexts where self-care takes place, including traditional healthcare settings (GP surgeries, clinics, hospitals), schools and colleges, the workplace, community hubs (such as youth centres), and other non-clinical settings.

It's important to note that the themes contained in each segment of the 'wheel' are not necessarily exclusive to that particular dimension alone. It was decided to organise the themes in this way based on the context in which they were mentioned during the workshops. For instance, there are some themes, such as 'Shared decision-making about how to manage LTC' (shown in 'Physical'), that are also relevant to several of the other segments.

The illustration, therefore, is intended to represent a conceptual model that can accommodate many different and overlapping themes into a common understanding of what constitutes self-care.

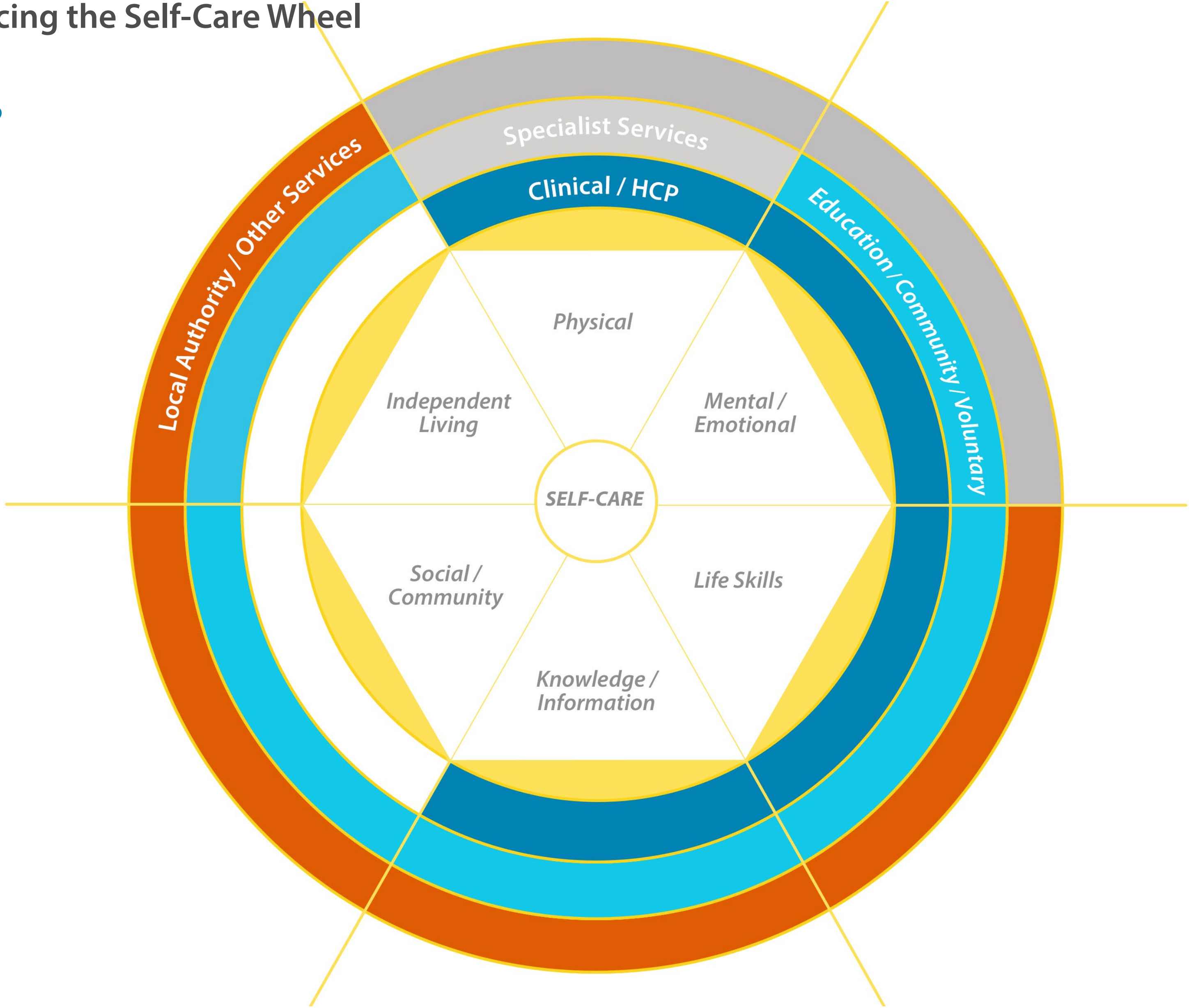
6.4 Visualising New Models of Self-Care

Illustration 6.4a



6.4.1 Introducing the Self-Care Wheel

Illustration 6.4b



6.4 Visualising New Models of Self-Care

This model directly informed the development of the 'Self-Care Wheel' (see illustration 6.4b). The Wheel can be used as an evaluative tool to assess the potential effectiveness of any given initiative or programme in addressing self-care. It can also be used as a tool by commissioners to build on existing service specifications and/or commission new initiatives/programmes that will meet the self-care needs of Londoners.

The Self-Care Wheel is premised on the idea that the more 'segments' or dimensions that are covered by a proposed intervention, the greater its overall effectiveness and sustainability. This model also reinforces a holistic view of health and wellbeing, and promotes a 'systems' approach as called for in the previous section (6.2 10 Key Points for Commissioners). To fully meet the needs of their population, commissioned services need to be able to demonstrate that they address all of the segments between them, and where this requires support from multiple services that people can easily access all services without additional assessment.

Traditional models of service delivery tend to take a compartmentalised approach, focusing on one segment at a time, as represented in illustration 6.4c.

6.4.2 New Self-Care Models: Case Studies

Although the number of case studies is limited, there are, however, some exemplary programmes across London that provide a holistic approach to self-care support. They have all been successful in integrating a range of services in easily accessible community hubs, and have been able to show positive health outcomes as a result.

While these programmes differ from each other (in terms of the 'menu of services' they offer), what they each have in common is that they all encompass multiple segments of self-care when mapped onto the Self-Care Wheel. They have, therefore, been selected as case studies, and are outlined below.

Programmes that Deliver Services:

6.4.2(i) The Well Centre, South London

The Well Centre is a 'youth health centre' — a combination of a GP practice and a youth centre — for young people aged between 11 and 20 years. Its staff includes GPs, Child and Adolescent Mental Health Service (CAMHS) nurses, and youth workers. The centre acts as 'one-stop shop' where young people can get physical health checks, mental health counselling, and support with personal and

6.4.2 New Self-Care Models: Case Studies

social issues; in addition, the centre provides access to information, organises awareness campaigns, and hosts various recreational and social events. It accepts both referrals from other services and 'drop-ins', and is able to refer people to specialist support services when required, (see illustration 6.4d).

6.4.2(ii) Dunraven School, Streatham

Dunraven School in South London runs a mentoring and peer support programme that successfully combines academic, emotional and social support. The programme actively engages students, school staff, and families, in raising young people's motivation, commitment to learning and engagement in education. It provides a safety net for vulnerable young people, (who may be dealing with health, social, or academic issues), by helping them develop personal skills, (such as building confidence, the ability to make choices and take responsibility, planning and goal-setting), in order to create a sense of resilience. In addition to supporting their emotional wellbeing, the programme offers guidance on vocational training, apprenticeship placements, and alternative options for broadening their learning experience, (see illustration 6.4e).

6.4.2(iii) Community Pharmacies, N-E London

The North-East London Local Pharmaceutical Committee (NELLPC) has developed an innovative new model of delivering healthcare that brings public health services directly into the local community, through the creation of 'community pharmacies'. Extending the scope of a traditional pharmacy, the community pharmacy is redefined from a place that simply delivers medicines — to a provider of integrated care, combining the physical and clinical aspects of health with the psychosocial, including behaviour change techniques and patient empowerment.

So, as well as providing health checks, vaccinations, and care for a range of LTCs (such as diabetes, cardiovascular and respiratory diseases), they also offer personalised care plans ('wellbeing plans') that are based on a 'bio-physical-social needs assessment' and co-created with the patients themselves. In addition, community pharmacies provide training, supervision, mentoring, coaching and support for clinicians, as well as patients, (see illustration 6.4f).

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6.4.2 New Self-Care Models: Case Studies

Programmes that Support Service Delivery:

6.4.2(iv) TalkLab, London

TalkLab in London is an interdisciplinary organisation that engages local people in a process of innovation and co-creation around the arts, technology, and healthcare. Their work challenges the assumption of 'users as passive consumers', and strives to renegotiate and restructure relationships between people who use services and HCPs, in a way that empowers both parties (see illustration 6.4g).

Through TalkLab, citizens, HCPs and commissioners have collaborated to develop a range of multi-media interventions that include:

// Better Conversations — improving the three way consultation between young people, their carers, and HCPs. Better Conversations provides young people with information to help them get the most out of their consultation, including helping them to understand and improve the process of shared decision-making. The programme also provides a coaching app for HCPs to enable them to be more responsive to young people's needs;

// The Better Life Experiment — a programme of workshops supported by a smartphone app directed at improving transition for young people with LTCs as they take on more responsibility for their care. The key aspect of this programme is the underlying peer support network that enables young people to connect with and learn from others experiencing the same condition.

// Re-thinking Transition — a series of inter-professional workshops to train healthcare professionals, (in primary, secondary and community care), to recognise and address the life skills that young people have said impact their ability to lead a healthy, active, and successful life. The programme focuses on four key themes: resilience, ability to have 'tricky' conversations, achieving life aspirations, and, integrating the management of a LTC into daily life.

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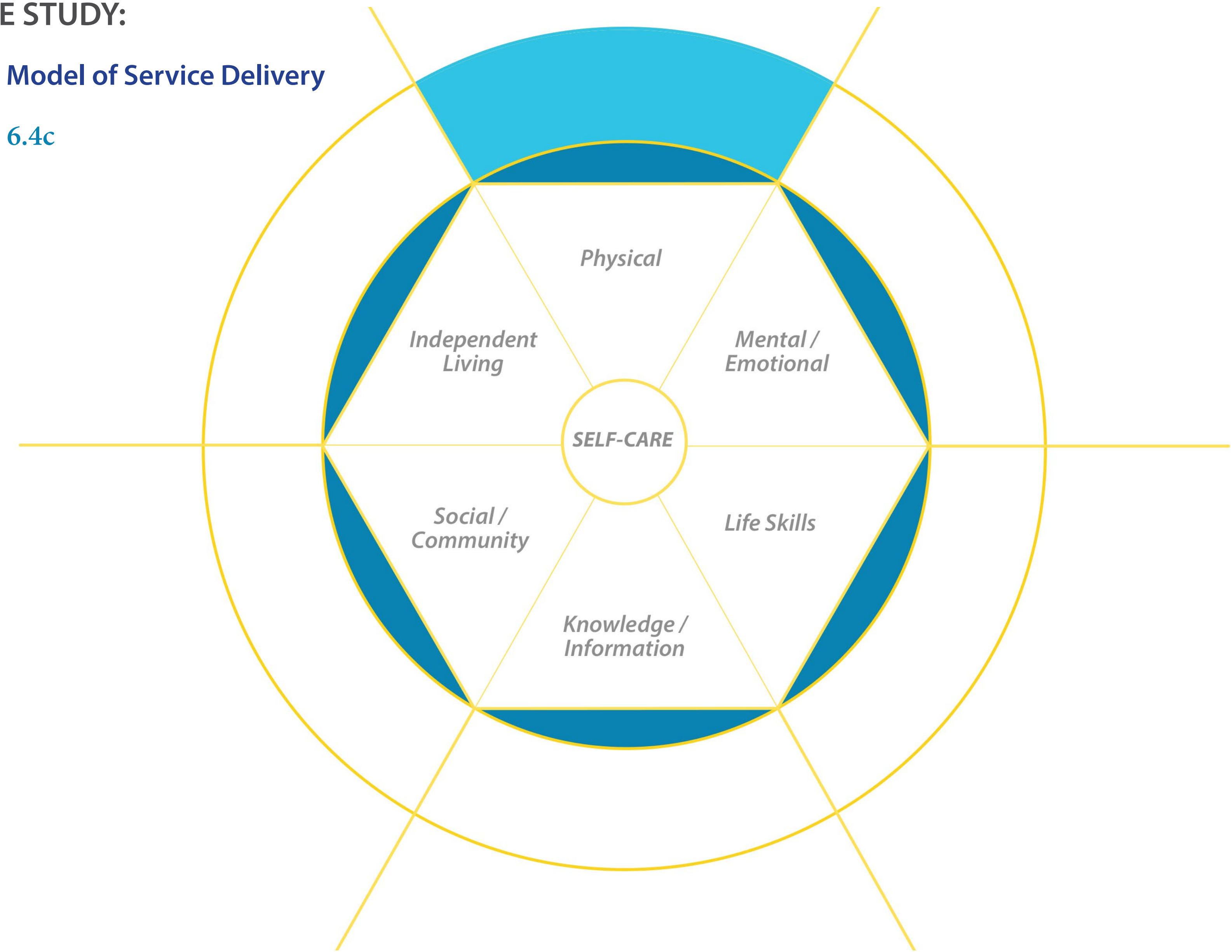
6.4.2 CASE STUDY:

Traditional Model of Service Delivery

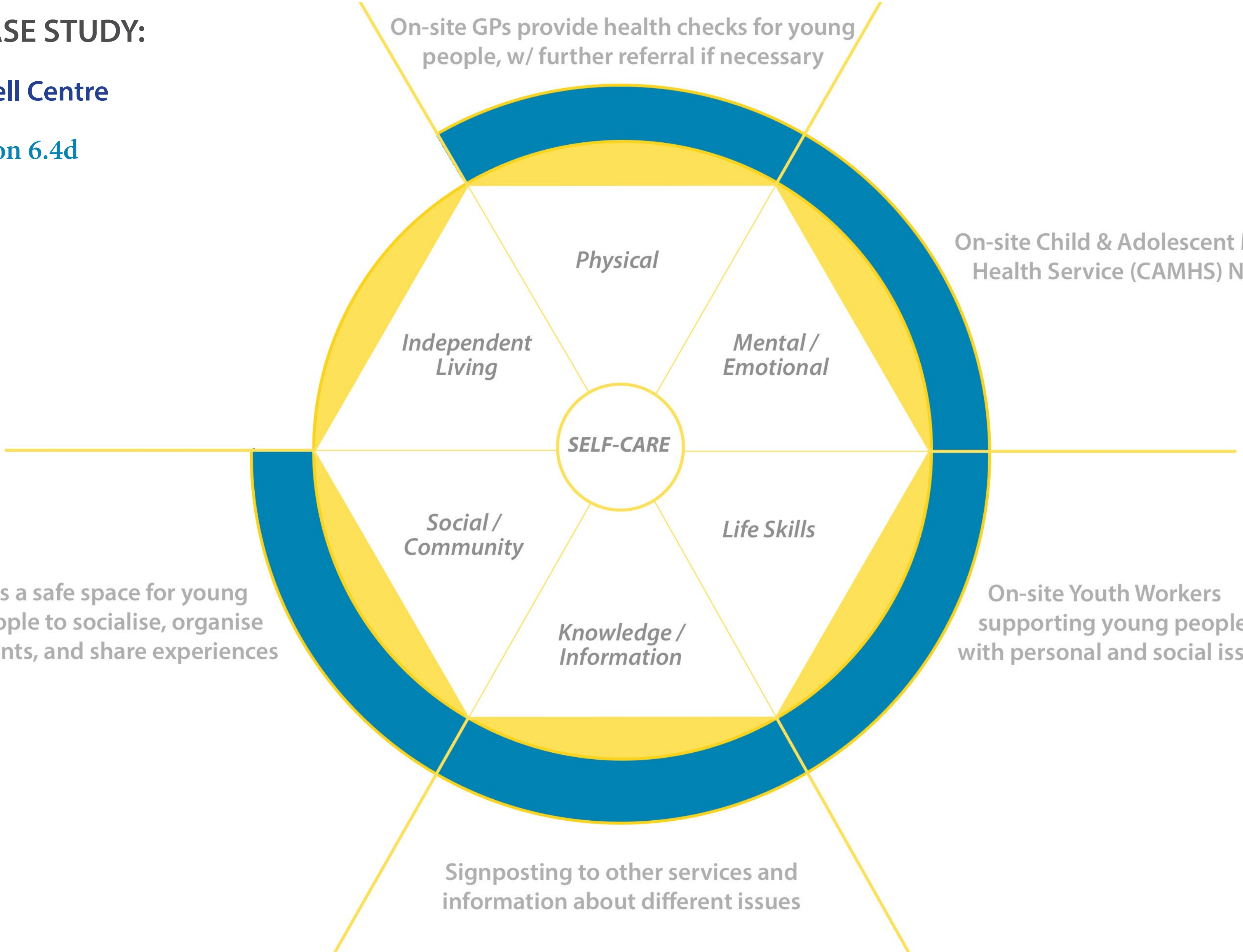
Illustration 6.4c



6.4.2 CASE STUDY:

(i) The Well Centre

Illustration 6.4d



On-site GPs provide health checks for young people, w/ further referral if necessary

On-site Child & Adolescent Mental Health Service (CAMHS) Nurse

On-site Youth Workers supporting young people with personal and social issues

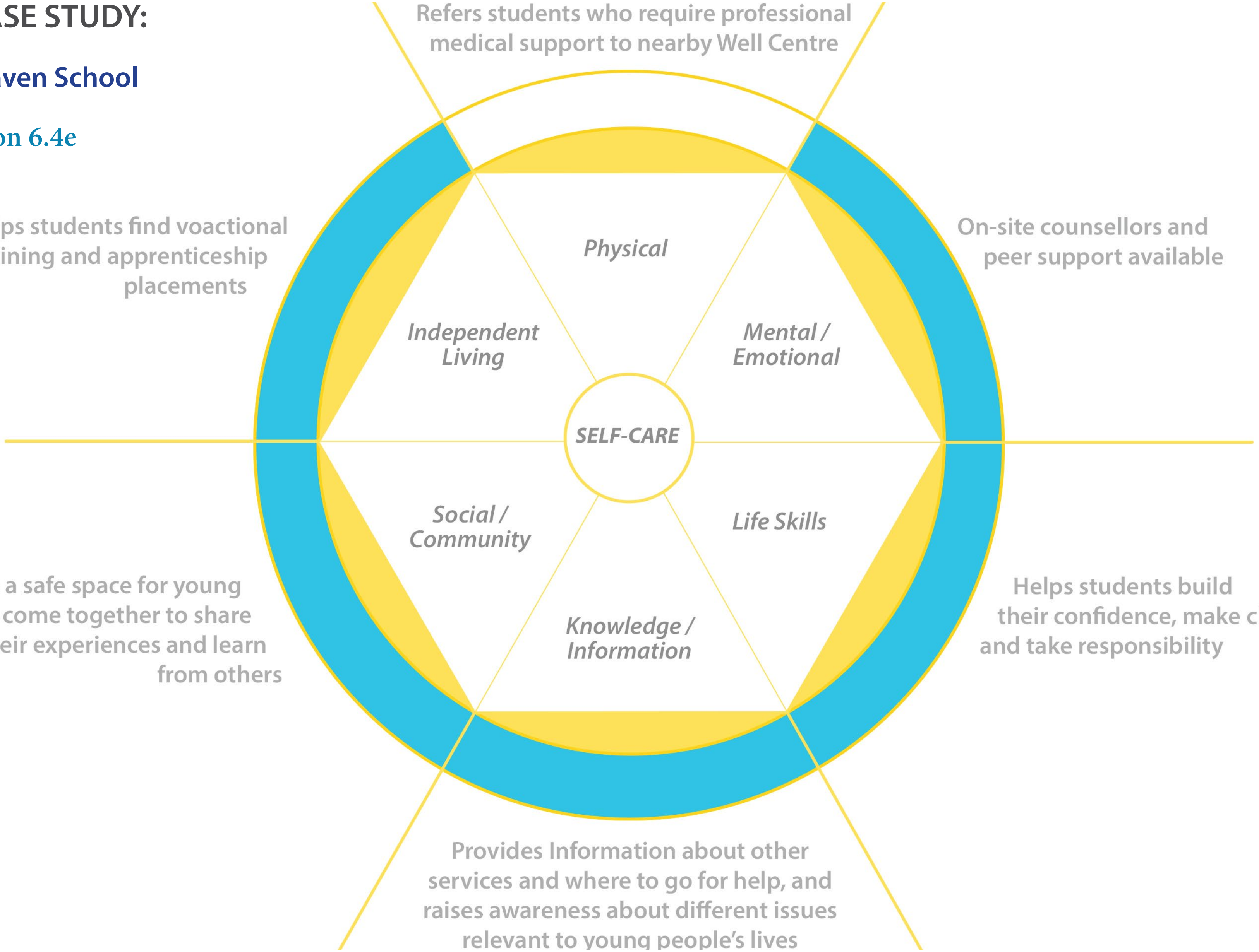
Signposting to other services and information about different issues

Provides a safe space for young people to socialise, organise events, and share experiences

6.4.2 CASE STUDY:

(ii) Dunraven School

Illustration 6.4e



Refers students who require professional medical support to nearby Well Centre

Helps students find voactional training and apprenticeship placements

On-site counsellors and peer support available

Provides a safe space for young people to come together to share their experiences and learn from others

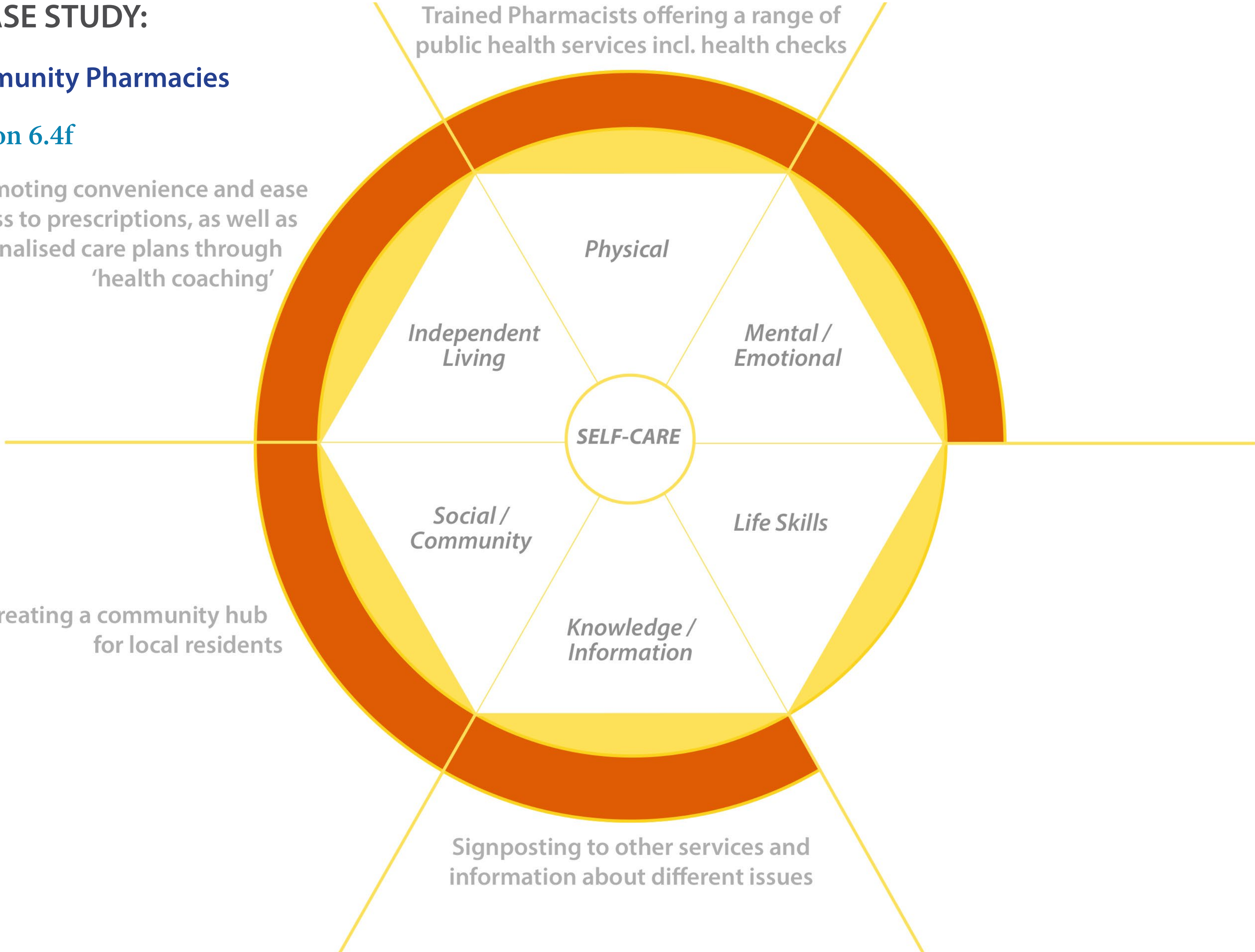
Helps students build their confidence, make choices and take responsibility

Provides Information about other services and where to go for help, and raises awareness about different issues relevant to young people's lives

6.4.2 CASE STUDY:

(iii) Community Pharmacies

Illustration 6.4f



Trained Pharmacists offering a range of public health services incl. health checks

Promoting convenience and ease of access to prescriptions, as well as personalised care plans through 'health coaching'

Creating a community hub for local residents

Signposting to other services and information about different issues

6.4.2 CASE STUDY:

(iv) TalkLab

Illustration 6.4g

Helping young people to live independently, make life choices, and take responsibility

Building young people's inner resilience, supporting their overall emotional wellbeing using mindfulness techniques, encouraging them to help others, and peer support

Provides a safe space for young people to socialise, organise events, and share experiences

Helping young people to cope with life's ups and downs, supporting them to have 'tricky' conversations, planning for the future, and managing risk

Community based workshops enable peer support and learning through shared experiences

6.5 Conclusion: Moving Forward

The Made in London project was designed and implemented with the aim of creating a framework for embedding self-care in the commissioning of services for young adults in London.

The proposed goal was to create a framework that would not only highlight priority areas and key recommendations that are needed to support self-care for young adults, but would also define a process, or methodology, that could be both transferrable and scaleable to other similar programmes across London. The approach taken to delivering this programme was key in this regard and was designed using the following principles: collaborative, evidence-based, asset-based, continuous and iterative.

Given the emphasis on collaboration and engagement, young adults were involved in the project from the outset in a process of shared decision-making. At the same time, they were provided with the necessary communication and facilitation skills to allow them to engage effectively in identifying needs, making recommendations, and shaping the programme agenda.

The process of engagement throughout the project was highly successful as young adults, partner organisations, HCPs, and other stakeholders came together — as equal partners — to discuss what self-care means and how to commission for self-care support.

The recommendations that emerged from the workshops supported the evidence that had been gathered during prior phases of the project and emphasised the importance of providing integrated care. Moreover, the outcomes supported the House of Care model as the basis for developing a self-care framework.

As well as highlighting priority areas, the final recommendations were distilled into ten key points for commissioners.The workshops highlighted the need to improve existing services, rather than calling for new services (that are currently unavailable).

Perhaps the most interesting outcome of the engagement workshops was the new and more holistic understanding of self-care that emerged. This was developed into the Self-Care Wheel, which is a tool to help commissioners and service providers design, build and evaluate both new and existing services in a way that addresses need and delivers efficient care. It demands integrated care, but also provides a framework which enables that care to be built around the needs of people. As an assessment tool, it focuses on patient outcomes and requires organisations to take a far more holistic view, looking beyond individual services by considering different dimensions of support

6.5 Conclusion: Moving Forward ... cont'd

that are needed at the same time.

The expectation is that the Made in London programme is one step in a longer journey. The next step will require commissioners to adopt both the recommendations and methodology used as they build new solutions that address the self-care needs of the communities they serve. The differences between these communities will require as many different solutions as attempts to create them.

Programmes that have utilised this approach and methodology are already delivering high-quality care across London. A few of these are highlighted in this report as examples that can offer inspiration to others taking up this challenge. The Senate would like to continue to share further examples via its website to support uptake of the recommendations. Clearly a 'lift and shift' approach will not be successful, but there will be learning from each that will be of value to others.

For more information and updates about this project, please visit:
www.londonsenate.nhs.uk/supporting-young-adults-to-self-care/

6.6 Acknowledgements

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Facilitators
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Made in London

New Approaches to Self-Care for Young Adults

NHS

London Clinical Senate