Professional Record Standards Body

Better records for better care

DIGITAL CARE AND SUPPORT PLAN STANDARD

FINAL REPORT

MARCH 2018

Acknowledgements

North West London Collaboration of CCGs (NWL CCGs)

The North West London Collaboration of CCGs is composed of eight Clinical Commissioning Groups: Brent, Hillingdon, Harrow, Central London, West London, Hounslow, Hammersmith and Fulham and Ealing CCGs. Within the sector, the NWL health and care partnership is made up of over 30 NHS and local authority organisations who plan, buy and provide health and care services for more than two million local residents across eight boroughs, spending around £4bn per year. NWL encompasses 400 GP practices, ten acute and specialist hospitals, two mental health trusts and two community health trusts. NWL is an Integrated Care Pioneer site and has a well-developed Whole Systems Integrated Care framework. The vision is to improve the quality of care for individuals, carers and families, empowering and supporting people to maintain independence and to lead full lives as active participants in their communities. This is being supported by three key principles: people will be empowered to direct their care and support and choose how and where care is received, GPs will be at the centre of organising and coordinating peoples' care, and systems will enable and not hinder the provision of integrated care.

Healthy London Partnership (HLP)

HLP was formed in April 2015 in response to the NHS Five Year Forward View and the London Health Commission's Better Health for London. It aims to take London from seventh in the global healthy city rankings to number one. It works across health and social care, the Greater London Authority, Public Health England, NHS England, London's councils, clinical commissioning groups, and Health Education England. All have united to amplify the efforts of a growing community of people and organisations that believe it is possible to achieve a healthier, more livable global city by 2020.

NHS Digital

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The Professional Record Standards Body

The independent Professional Record Standards Body (PRSB) was registered as a Community Interest Company in May 2013 to oversee the further development and sustainability of professional record standards. Its stated purpose in its Articles of Association is: "to ensure that the requirements of those who provide and receive care can be fully expressed in the structure and content of health and social care records". Establishment of the PRSB was recommended in a Department of Health Information Directorate working group report in 2012.

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Glossary of Terms

Term / Abbreviation	**What it stands for**
AoMRC	Academy of Medical Royal Colleges
CCG	Clinical Commissioning Groups
CCIO	Chief Clinical Information Officer
CDGRS	Clinical documentation and generic record standards
CIO	Chief Information Officer
CPAG	Clinical and Professional Advisory Group
CRO	Clinical Responsible Officer

CSP	Care and support plan. Used interchangeably with DCSP
DCSP	Digital care and support plan. Used interchangeably with CSP
EHR	Electronic Health Record
EPR	Electronic Patient Record
ETTF	Estates and Technology Transformation Fund
FHIR	Fast Healthcare Interoperability Resources
GP	General Practitioner
GPSoC	GP System of Choice
HIG	RCGP Health Informatics Group
HIU	Health Informatics Unit
HL7	Health Level 7
HLP	Healthy London Partnership
ICR	Integrated care record. Used interchangeably with IDCR
IDCR	Integrated digital care record. Used interchangeably with ICR
LDR	Local Digital Roadmap
Metadata	A set of data that describes and gives information about other data
NIB	National Information Board
NHS	National Health Service
NHSCC	NHS Clinical Commissioners
NHSD	NHS Digital
NWL	North West London
NWL CCGs	North West London Collaboration of Clinical Commissioning Groups

PID	Project Initiation Document
PRSB	Professional Record Standards Body for health and social care
RCGP	Royal College of General Practitioners
RCN	Royal College of Nursing
RCOT	Royal College of Occupational Therapists
RCP	Royal College of Physicians
SNOMED-CT	Systematized Nomenclature of Medicine - Clinical Terms
STP	Sustainability and Transformation Plan
ToC	Transfer of Care
WSIC	Whole Systems Integrated Care

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1. Purpose and introduction

1.1. Purpose

The digital care and support plan project is an important piece of work, which aims to set a national standard for recording information pertinent to personalised care and support planning for implementation in both health and social care.

The aim is to move from the currently largely paper-based care and support plans to standardised structured digital communications, which will enable care and support plans to be created and maintained by individuals and health and care professionals working in different settings. The terms used in the standard care and support plan will provide a common language acceptable to patients, service users and health and social care professionals across the spectrum. This will enable sharing of key information in a person-centred way.

Care and support plans span all care settings (primary, acute, community, mental health and social care). They are generally required by people with long-term conditions or complex needs which are being self-managed, or managed with multi-disciplinary support.

Currently where care and support plans are digital, they tend to be held on a single system with little or no integration with other health or social care systems. This results in duplication and fragmentation.

This standard for digital care and support plans is expected to enable interoperability between health and social care IT systems and enable access to patients/service users. This step change will enable care and support plans to be created and updated dynamically and is expected to result in the following outcomes:

- Improved continuity of care by communicating relevant information more quickly, which should help people to get the right information and support when they need it.
- Empower people by enabling them to direct their care and support.
- Provide a holistic picture of an individual's strengths, needs, goals and actions, enabling individuals, carers, next of kin, as well as health and care professionals to provide appropriate support to enable people to remain healthier for longer.
- Improve safety by reducing transcription errors through re-use of key data.
- Improve safety by recording and sharing information about what to do in a deteriorating or crisis situation.
- Improve individuals' experience by ensuring key information about them is available to care professionals wherever and whenever it is needed.

1.2. Introduction

This project was commissioned by the North West London collaboration of Clinical Commissioning Groups (NWL CCGs) and has been a collaborative effort between the PRSB project team, NWL CCGs, NHS Digital and the Healthier London Partnership (HLP). Further stages of work, through to

implementation, will be commissioned by NHS Digital. The Professional Records Standards Body (PRSB) was commissioned to consult with individuals, health and social care professionals, suppliers and commissioners to ensure that the standard meets their needs. The work was conducted in partnership with the Royal College of Physicians (RCP) Health Informatics Unit (HIU). Leadership was provided by members of the Royal College of General Practitioners (RCGP), the Royal College of Nursing (RCN), Adult Social Care and the RCP Patient and Carer Network. A broader multidisciplinary team was brought together through the project board and included members of the Royal College of General Practitioners Collaborative Care and Support Planning Champions' Network, NHS Digital, NWL Collaboration of CCGs, the Royal College of Nursing, the Registered Nursing Home Association, the Royal College of Occupational Therapists, and the Association of Directors of Adult Social Services.

Care and support plans are the output of a collaborative care planning process, carried out in consultation and with the agreement of the person and their family/carer. They aim to maximise the person's capacity to self-care/self-manage and need to be accessible, personalised and easy to understand.

Care and support plans cover what is most important to the person. This includes personal and health related goals, strengths or assets, problems, needs and activities or actions linked to achieving the goals and addressing the problems and needs. Using standards in electronic health care records allows information to be recorded, exchanged and accessed consistently across care settings, to deliver high-quality care to individuals.

The scope of this project was set out in the Project Initiation Document (PID) to include:

- Development of headings and definitions for a generic integrated digital care and support plan, together with information models identifying the relationship between headings, cardinality and value sets.
- Terms which are acceptable to individuals and the spectrum of health and care professionals.
- Implementation guidance, including definition and common language of the business processes involved in creating and maintaining generic care and support plans.
- The identified care and support plan structure will need to be suitable for use across acute, primary, community, mental health and social care settings, including care providers e.g. care homes and domiciliary care.
- The care and support plan structure will include anticipatory and escalation plans and advance preferences for care.

The scope excludes:

- Standards for use case or condition specific care plan content e.g. diabetes or end of life care, (although the included use cases do illustrate how this standard can be used for patients with long term conditions).
- Care plans used by individual disciplines or services to manage specific aspects of care (e.g. hospital hip fracture care pathway or plan, district nursing wound management care plan).
- Care and support plans set up by individuals to manage their own social care, where these do not have any health care input.

- Integrated care records, such as the summary care record and similar local shared care records.
- Development of technical specifications and design and development of system solutions (although this project will provide information models which can form the basis for technical specifications).
- Implementing standardised coding in electronic systems.
- Information governance arrangements.
- Financial assessments, personal budgets and allocation of resources.
- Care plans for children and young people.

The integrated digital care and support plan standards developed by this project will be used to create a technical specification by NHS Digital, which will in turn be implemented in North West London as a national accelerator site, supported by system vendors. Both this standard and the NHS Digital technical specification will be published so that it can be used by other organisations and communities to implement interoperable digital care and support plans.

This document is the project final report, describing the methods used, outputs from the consultation, the recommended record structure and associated recommendations to NHS Digital.

2. Methodology

The project was conducted according to the PRSB process and assurance criteria. In addition to the usual PRSB network, NWL has established a Clinical and Professional Advisory Group (CPAG) to engage interested and knowledgeable stakeholders throughout the project.

2.1. Project initiation

A project brief was first produced, before being refined and extended into a project initiation document (PID). The PID gave the direction and scope of the project and forms the 'contract' between the project management team and the project board.

The PID also included an engagement and communications plan. This plan set out how engagement with stakeholders would be carried out from the start to ensure that they were aware of the project, engaged in the consultation and ready to endorse and implement the final standard.

A 'Ryver' discussion forum was set up on the INTEROPen[1] website. This was used to engage a clinical and professional advisory group (CPAG) with the hope of bringing together key stakeholders in health and social care as well as technical experts from industry. The group was advertised via existing care and support planning networks, such as the RCGP Collaborative Care & Support Planning Champions' Network and via PRSB networks. Drafts of the project documents were posted on this forum.

2.2. Evidence review

The evidence review identified existing models including international care plan models (e.g. 'Contsys'), the NHS Digital 'Using SNOMED CT in care planning' document, NWL and other local care and support plan documents, which were mapped to the PRSB/AoMRC headings.

The evidence review built on the business analyst patient engagement workshop commissioned by NWL. This included observation and discussion with individuals and health and care professionals working with integrated care plans in different settings (hospital, primary care, social care and mental health) about the process for creating and maintaining care plans. It also analysed how it works currently and the improvements that could be made with interoperable systems. This was used to create business requirements to include in draft implementation guidance.

To ensure that the evidence review was wide-ranging and to engage as many of those involved in developing local integrated care and support plans as possible, the project team engaged with Coalition for Collaborative Care (C4CC), National Voices, the NHS England personalised care team, the integrated care pioneers and others who expressed an interest in the project.

A literature review was undertaken and keys findings extracted. Search terms were reviewed and refined and used to identify relevant research papers (see Appendix A).

2.3. Consultation workshops

The above mappings and draft business requirements were discussed with clinical/social care advisors and an initial draft was agreed for consultation.

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[1] https://interopen.ryver.com

A consultation workshop was held on 11 July 2017 with key stakeholders, including patients/service users and carers, front line health and care professionals, informaticians and industry representation (attendees are listed in Appendix C) to review the draft requirements.

The workshop was also used to begin to explore implementation and clinical safety issues.

Following the workshop the outcomes were discussed with the project clinical/social care advisors. This informed the second draft of standard headings and content definitions, information models and the first draft implementation guidance.

Information models, in the form of word documents, were drafted by the project team and reviewed with the project clinical/social care advisors. The models were informed by the evidence review and the consultation workshop. Business values were derived from existing PRSB information models, where relevant.

The first draft of the information model was shared with the NHS Digital terminology and messaging leads for their review and feedback. The terminology lead has mapped headings to SNOMED CT and provided additional subsets, where relevant. These have been reviewed by clinical/social care advisers and feedback provided on the proposals made.

The project team held a meeting to review the information models and inform development of the draft implementation guidance. The implementation guidance includes issues identified from the evidence review and workshop which relate to implementation of the headings. They are not intended to be comprehensive, but just issues identified at this stage. It is expected that this guidance will be updated once pilot implementations are undertaken, to include the lessons learnt from them.

2.4. Online survey consultation

Following the consultation workshop, feedback was used by the project team to develop an updated version for wider consultation. The PRSB project team designed an online survey, to obtain the views of frontline care professionals, patients/service users and carers (see Appendix C for a breakdown of the respondents).

Survey Monkey was used to conduct the online consultation. The survey asked for feedback on:

a) the appropriateness and usefulness on each of the draft headings and descriptions
b) additional sub-headings that may be required
c) structure of the ‘about me’ heading
d) need for associating with other plans
e) restricting access to the care and support plan
f) any additional issues

The survey was sent via personalised emails to more than 200 identified stakeholders from patient and carer groups, Royal Colleges, specialist societies and other professional bodies in health and social care. It requested them to complete the survey and distribute more widely among colleagues using formal and informal networks. The survey and accompanying consultation document were

hosted on the Professional Record Standards Body (PRSB) website and the Clinical & Professional Advisory Group (CPAG), and promoted via the Royal College of Physicians, PRSB and partner organisations' social media channels.

The survey ran from 7 August 2017 to 13 September 2017, with 623 individuals participating. The survey responses were collated and analysed (both quantitative and qualitative) and recommendations produced with guidance provided from the project clinical/social care advisors.

The analysis was used in conjunction with the workshop outputs to inform the recommendations provided. The recommendations were based on the following considerations:

- a greater majority of respondents across all cohorts demonstrate a preference for one position or option being offered over an alternative;
- stronger rationale for an alternative minority position is demonstrated; or,
- a suggestion is not assessed as practical to implement at this time.

Feedback was also sought on the draft information models from health informatics leads at specialist societies, informaticians and CCIOs. This feedback is not reported in this document due to it being more of a technical nature, but was used to inform the expert group review.

2.5. Expert Group Review

Following the consultation, the draft integrated care and support plan headings, information model and implementation guidance were reviewed by an expert group, involving industry, professional and patient/service user bodies, and used to resolve outstanding issues. The meeting was held on 20 October 2017 (see Appendix C for a list of attendees). This resulted in a final draft version of the information model and implementation guidance.

2.6. Development of case studies

It was expected that there was work underway nationally by various services to implement digital care and support plans. Potential case study sites were identified via the RCGP Collaborative Care & Support Planning Network of Champions, NWL and CPAG and via communications sent out in newsletters. They were assessed and ranked according to best fit by the project team and agreed with the project board. They were approached and consulted on the local work done in integrated care planning.

The project team has been in contact with Hillingdon CCG, Bromley Healthcare, East London NHS Foundation Trust, Islington CCG, Northumbria NHS Trust, NHS Newcastle Gateshead CCG, South Somerset, Oxfordshire CCG and Catalyst Stockton-On-Tees. Consultation with these services, in part, informed the development of this standard. Other services were identified also, however, without a positive response for further discussions.

Case studies were developed to showcase progress that has been made in relation to integrated care planning. The case study report is published separately from the final report and includes illustration of care planning work done at East London NHS Foundation Trust, Hillingdon CCG, South Somerset Symphony Programme and Oxfordshire CCG.

2.7. Development of example use cases

Care professionals from appropriate specialties were asked to help compose specific use case examples to provide illustration of how the generic model could be applied in different use cases, including long-term conditions, mental health issues, learning disabilities, and social care (see Appendix B).

3. Headings and definitions

3.1. New headings developed in the digital care and support plan standard project

This section sets out the new headings defined in the digital care and support plan project. The main set of headings is the individual's personalised care and support plan. In addition, new headings have also been defined for other information that is integral to supporting personalised care and support planning:

- About me – this is the proportionate information which an individual feels it is important to communicate about their needs, strengths, values and preferences to others providing care and support. Where relevant, additional information may come from family members, carers and professionals. This information should always be at the forefront of each plan.
- Contingency plan – this is a plan of what should be done if the individual's condition or other circumstances get worse.
- Additional supporting plan – this is an additional/specific care plan (e.g. wound management, dietetics), which the individual and care professional consider should be shared with others providing care and support to the individual.

It is not anticipated that information will need to be recorded under all headings in all circumstances, only where they are relevant to a specific person.

The metadata about a care and support plan (the individual it is developed with, the care professional and organisation supporting its completion, date and version number) must be included in each entry of the care and support plan for it to be shared. Other headings are optional.

The order or sequence in which the headings appear in EHR systems and communications can be agreed locally by system providers and end users. The terms used in EHRs may be different to the national standard, but should map to the national standard for the care and support plan to be communicated electronically.

Personal demographics, GP practice, other relevant contacts (e.g. care coordinator, carer, etc.), and existing services and care could also be included with the care and support plan. These are covered by existing PRSB headings.

The records for about me, care and support plan and contingency plan need to be given prominence in an electronic record so that they are can be easily viewed by those providing care and support, and direct and inform the care and support provided.

About me	
About me	This is a record of the things that an individual feels it is important to communicate about their needs, strengths, values and preferences, etc to others providing support and care.
Supported to write this by	Where relevant, this is a record of name, relationship/role and contact details of the person who supported the individual to write this section e.g. carer, family member, advocate, professional.
Date	This is a record of the date that this information was last updated.

Care and support plan *(This records the decisions reached during a conversation between the individual and a health and care professional about future plans and also records progress and changes made since the last planning session.)*	
Strengths	Any strengths and assets the individual has that relate to their goals and hopes about their health and wellbeing.
Needs, concerns or health problems	Needs, concerns or health problems an individual has that relate to their health and wellbeing.
Goals and hopes	The overall goals, hopes, aims or targets that the individual has. Anything they want to achieve that relates to their future health and wellbeing. Each goal may include a description of why it is important to the person. Goals may also be ranked in order of importance or priority to the individual.
Actions and activities	Actions or activities the individual or others plan to take to achieve the individual's goals and the resources required to do this. For each action the following may be identified: a) Stage goal – a specific sub-goal that is related to the overall goal as agreed by the person in collaboration with a professional b) What – what the action is and how it is to be carried out? c) Who – name and designation (e.g. person, carer, GP, OT, etc.) of the person, or a team, carrying out the proposed action, and, if relevant where action should take place d) When – planned date, time, or interval, as relevant e) Suggested strategies for potential problems f) Status – Not started, Started, Completed, Not applicable g) Confidence – how confident the person feels to carry it out h) Outcome – the outcome of the stage goal i) Date when action/activity record was last updated j) Review date – when the stage goal and action need to be reviewed
Outcomes	Outcomes of each of the individual's goals, aims and targets. Includes comments recorded by the individual, date and status: fully achieved, partially achieved, not achieved, on-going, no longer applicable.
Agreed with person or legitimate representative	Indicates whether the plan was discussed and agreed with the person or legitimate representative.
Planned review date/interval	This is the date/interval when this information will next be reviewed.
Responsibility for review	This is a record of who has responsibility for arranging review of this

	information. Should include their name, role and contact details.
Care funding source	A reference to the funding source and any conditions or limitations associated.
Other care planning documents	Reference other care planning documents, including the type, location and date. This may include condition-specific plans, advance care plans, end of life care plan, etc.

Person completing record and date it was completed needs to be recorded for each update made to the care and support plan.

Person completing record	This is the person contributing to the care and support plan. Should include their name, role, grade, specialty, organisation, professional identifier, date and time completed, contact details.
Date this plan was last updated	This is a record of the date that this care and support plan was last updated.

Contingency plan *(These are the things to do and people to contact should an individual's health or other circumstances get worse.)*	
Contingency plan name	Name of the contingency plan – what condition or circumstances it is addressing.
Trigger factors	Signs to watch out for that may indicate a significant change in health or other circumstances.
What should happen	To record guidance on specific actions or interventions that may be required or should be avoided in specific situations. This may include circumstances where action needs to be taken if a carer is unable to care for the individual.
Who should be contacted	Who should be contacted in the event of significant problems or deterioration in health or wellbeing including, e.g. name, relationship and contact details of persons.
Anticipatory medicines/ equipment	Medicines or equipment available that may be required in specific situations and their location.
Planned review date/interval	This is the date/interval when this contingency plan will next be reviewed.
Responsibility for review	This is a record of who has responsibility for arranging review of this information. Should include their name, role and contact details.
Date this plan was last updated	This is a record of the date that this contingency plan was last updated.
Agreed with person or legitimate representative	Indicates whether the plan was discussed and agreed with the person or legitimate representative.
Person completing record	This is the person contributing to the care and support plan. Should include their name, role, grade, specialty, organisation, professional identifier, date and time completed, contact details

People at varying stages of different long-term conditions may also wish to consider their preferences in relation to emergency care and treatment, including CPR decisions. To do so, there is a process known as ReSPECT[2]. ReSPECT has been developed by a group of stakeholders, including representatives of patients and the public, with a leading role taken by the Resuscitation Council (UK)[3].

[2] http://www.respectprocess.org.uk
[3] https://www.resus.org.uk

Advance statements and directives, preferences (e.g. places of care and death) and lasting power of attorney may also be included in such plans. These are covered by existing PRSB headings (see section 3.2).

The information model below is for plans which are unable to follow the format set out above and will enable additional supporting plans to be shared where applicable to do so. This approach should be taken only where it is not possible to follow a standard care and support plan format, e.g. a wound management plan where a diagram with location of the wound is included as part of the plan.

Additional supporting plan *(An embedded record of any additional care plans which the individual and/or care professional consider should be shared with others providing care and support.)*	
Additional supporting plan name	The name of the particular additional supporting plan, e.g. dieticians plan, wound management plan, discharge management plan.
Additional supporting plan content	This is the content of any additional care and support plan which the individual and/or care professional consider should be shared with others providing care and support. It should be structured as recommended for the care and support plan and if it contains additional detail, it may be referenced here.
Person completing record	This is the person contributing to the care and support plan. Should include their name, role, grade, specialty, organisation, professional identifier, date and time completed, contact details
Planned review date/interval	This is the date/interval when this information will next be reviewed.
Responsibility for review	This is a record of who has responsibility for arranging review of this information. Should include their name, role and contact details.
Date this plan was last updated	This is a record of the date that this information was last updated.

3.2. Other information needed to support the care planning process

When we met with communities leading on electronic care and support planning, we found that the content of the record used is much wider than the care and support plan (CSP). It is often called an integrated digital care record. The need for an integrated record was also flagged when we consulted with individuals and professionals – they said that other information would be needed to inform the care planning process. The information that was identified comes from the individual's existing health and social care records. This indicates that the care and support plan should form part of an integrated care record, so that the other information needed is also available to those participating in the planning process. Standard PRSB headings already exist for recording this information. There is no need to duplicate this information as it should be possible to automatically extract it from existing electronic health and care records. In circumstances when a printed hard-copy of the care and support plan is required, however, it is important that the care and support plan does have all of the applicable headings below reproduced to ensure there is adequate context and information available.

We recommend that these headings in the care record should be available to those participating in the care and support planning process, including the individual and carer or family members, together with the care and support plan. It should be possible to combine these headings with a care and support plan into a role based output or a 'view', so that those involved in the care planning process do not have to search through the individual's record to find them. For example, we found that information on relevant contacts is often included when viewing a care and support plan and that trends in HbA1c results may be included in an output along with the care and support plan for an individual with diabetes.

Personal demographics	
Person name	The full name of the person.
Person preferred name	The name by which a person wishes to be addressed.
Person alias	Record details where a person is known to use assumed identities to access health/care services.
Date of birth	The date of birth of the person.
Sex	The person's phenotypic sex. Determines how the person will be treated clinically.
Gender	The person's stated gender (how the person wishes to portray themselves).
Ethnicity	The ethnicity of a person as specified by the person.
Religion	The religious affiliation as specified by the person.
NHS number	The unique identifier for a person within the NHS in England and Wales.
Other identifier	Country specific or local identifier, e.g., Community Health Index (CHI) in Scotland, Health and Care Number (H&C Number) in Northern Ireland. Two data items: type of identifier and identifier.
Person address	Person's usual place of residence.
Person email address	Email address of the person.
Person telephone number	Telephone contact details of the person. To include, e.g., mobile, work and home number if available.

Relevant contacts	
Name	The name of the person.
Relationship / role	The personal relationship (e.g., next of kin, in case of emergency contact, lasting power of attorney, dependants, informal carers etc.) or the professional role (e.g., social worker, hospital clinician, care coordinator, key worker, Independent Mental Capacity Advocate (IMCA) etc.) the individual has in relation to the person.
Contact details	Contact details of the person (e.g. telephone number, email address etc).

GP practice	
GP practice identifier	The identifier of the registered GP Practice.
GP practice details	Name and address of the person's registered GP Practice.
GP name	Where the person or person's representative offers the name of a GP as their usual GP.

Individual requirements	
Individual requirements[4]	Individual requirements that a person has. These may be communication, cultural, cognitive or mobility needs e.g., level of language (literacy); preferred language (interpreter required); bariatric ambulance required; support for any disability or impairment etc. Accessible information standard (accessible information - communications support, accessible information - requires communications professional, accessible information - requires specific contact method, accessible information - requires specific information format).

Legal information	
Consent for information sharing[5]	This is a record of consent for information sharing. It should state the purpose and scope of the consent. Where consent has not been obtained or sought, the reason why must be provided. Include best interests decision where person lacks capacity
Lasting power of attorney for personal welfare or court-appointed deputy (or equivalent)	Record of one or more people who have been given power (LPA) by the person when they had capacity to make decisions about their health and welfare should they lose capacity to make those decisions. To be valid, an LPA must have been registered with the Court of Protection. If life-sustaining treatment is being considered the LPA document must state specifically that the attorney has been given power to consent to or refuse life-sustaining treatment. Details of any person (deputy) appointed by the court to make decisions about the person's health and welfare. A deputy does not have the power to refuse life-sustaining treatment.
Deprivation of Liberty Safeguards or equivalent	Record of Deprivation of Liberty Safeguards (DoLS) or equivalent, including the reasons for this, and how it is being recorded.
Mental Health Act or	Record where a person diagnosed with a mental disorder is formally detained under the Mental Health Act or equivalent, including the section

[4] This is a coded information about specific requirements and therefore differs from the 'About me' section.

[5] See: *Information sharing for integrated care and new models of care: a blueprint*. https://digital.nhs.uk/information-governance-alliance/resources/information-sharing-resources

equivalent status	number and start date, start time and end date. If person subject to Community Treatment Order or Conditional Discharge (or equivalent) record here.
Advance decision to refuse treatment (ADRT)	A record of an advance decision to refuse one or more specific types of future treatment, made by a person who had capacity at the time of recording the decision. The decision only applies when the person no longer has the capacity to consent to or refuse the specific treatment being considered. An ADRT must be in writing, signed and witnessed. If the ADRT is refusing life-sustaining treatment it must state specifically that the treatment is refused even if the person's life is at risk.
Organ and tissue donation	Whether the person has given consent for organ and/or tissue donation or opted out of automatic donation where applicable. The location of the relevant information/documents.
Safeguarding issues	Any legal matters relating to safeguarding of a vulnerable child or adult, e.g., child protection plan, protection of vulnerable adult.

Safety alerts	
Risks to self	Risks the person poses to themselves, e.g., suicide, overdose, self-harm, self-neglect.
Risks to others	Risks to care professionals or others.
Risk from others	Details of where a child is at risk from an identified person e.g. family member etc.

Social context	
Household composition	E.g. lives alone, lives with family, lives with partner, etc. This may be free text.
Access	Special access requirements e.g. key safe, coded lock, which door to use, stretcher access, etc.
Lifestyle	The record of lifestyle choices made by the person which are pertinent to his or her health and wellbeing, e.g. the record of the person's physical activity level, pets, hobbies, and sexual habits.
Smoking	Latest or current smoking observation.
Alcohol intake	Latest or current alcohol consumption observation
Drug/substance use	Latest or current drug/substance use observation
Social circumstances	The record of a person's social background, network and personal circumstances, e.g. housing, religious, ethnic and spiritual needs, social concerns and whether the person has dependents or is a carer. May include reference to safeguarding issues that are recorded elsewhere in the record.
Services and care	The description of services and care providing support for a person's health and social wellbeing. If required, should identify specific individuals.

Diagnoses	
Diagnosis	Confirmed active diagnosis/symptom.
Stage	The stage of the disease where relevant.

Awareness of diagnosis	Description of the level of awareness the person and or their carer/family has regarding their diagnosis.

Problems and issues	
Problems and issues	Summary of problems that require investigation or treatment. This would include significant examination findings which are likely to have relevance, yet are not a diagnosis. In mental health and psychiatry, this may be the place for formulation.
Comment	Any further textual comment to clarify, such as statement that information is partial or incomplete.

Medications and medical devices	
Medication name	May be generic name or brand name (as appropriate).
Form	E.g. capsule, drops, tablet, lotion etc.
Route	Medication administration description (oral, IM, IV, etc.): may include method of administration, (e.g., by infusion, via nebuliser, via NG tube).
Site	The anatomical site at which the medication is to be administered. Comment: e.g. "Left eye"
Method	The technique or method by which the medication is to be administered.
Dose amount description	A description of the medication single dose amount e.g. "30 mg" or "2 tabs".
Dose timing description	A description of the frequency of taking or administration of a medication dose. e.g. "Twice a day", "At 8am 2pm and 10pm".
Dose directions description	A single plain text phrase describing the entire medication dosage and administration directions including dose quantity and medication frequency. Comment, e.g., “1 tablet at night or “2mg at 10pm”. This is the form of dosage direction text normally available from UK GP Systems
Additional instructions	Allows for: * requirements for adherence support, e.g., compliance aids, prompts and packaging requirements * additional information about specific person requirements, e.g., unable to swallow tablets, medicines, e.g., where specific brand required
Indication	Reason for medication being prescribed, where known.
Comment/recommendation	Suggestions about duration and/or review, ongoing monitoring requirements, advice on starting, discontinuing or changing medication.
Dose direction duration	Recommendation of the time period for which the medication should be continued, including direction not to discontinue.
For medications that have been changed, i.e. additions, amendments and discontinued, in addition to the above, also record:	
Description of amendment	Where a change is made to the medication i.e. one drug stopped and another started or e.g. dose, frequency or route is changed.
Indication (for medication change)	Reason for change in medication, e.g. sub-therapeutic dose, person intolerant.
Use the following heading for medical devices that do not have representation in the NHS dictionary of medicines and medical devices (dm+d):	
Medical devices	Any therapeutic medical device of relevance that does not have representation in the NHS dictionary of medicines and medical devices (dm+d).

Investigation results	
Investigation	The investigation performed.

Investigation result	For each investigation, the result of the investigation (this includes the result value, with unit of observation and reference interval where applicable and date).

Allergies and adverse reactions	
Causative agent	The agent such as food, drug or substances that has caused or may cause an allergy, intolerance or adverse reaction in this person.
Description of reaction	A description of the manifestation of the allergic or adverse reaction experienced by the person. For example, skin rash, swelling at injection site etc.
Type of reaction	The type of reaction experienced by the person (allergic, adverse, intolerance).
Severity	A description of the severity of the reaction.
Certainty	A description of the certainty that the stated causative agent caused the allergic or adverse reaction.
Evidence	Results of investigations that confirmed the certainty of the diagnosis. Examples might include results of skin prick allergy tests.
Probability of recurrence	Probability of the reaction (allergic, adverse, intolerant) occurring.
Date first experienced	When the reaction was first experienced. May be a date or partial date (e.g. year) or text (e.g. during childhood).

Measurements (May be self-monitored)	
Height	Height in cm
Weight	Weight in kg
Vital signs	The record of essential physiological measurements, e.g. heart rate, blood pressure, temperature, pulse, respiratory rate, level of consciousness. Use of National Early Warning Score (NEWS) chart where appropriate.

Person completing record	
Name	The name of the person completing the record, preferably in a structured

	format.
Role	The role the person is playing within the organisation at the time record was updated.
Grade	The grade of the person completing the record
Specialty	The main specialty of the person completing the record.
Professional identifier	Professional identifier for the person completing the record e.g., GMC number, HCPC number, etc. or the personal identifier used by the local organisation.
Date and time completed	The date and time the record was updated.
Contact details	Contact details of the person completing the record. For example a phone number, email address. Contact details are used to resolve queries about the record entry.

4. Implementation guidance

Purpose

4.1 This document provides implementation guidance to inform those implementing digital care and support plans. It is drawn from the evidence review and consultation carried out during the project. The need for standards for care and support plans is to enable them to be shared electronically between individuals and carers and those providing care and support across different care settings. This will mean that they are available whenever and wherever needed, including in an emergency, and that any updates can be quickly and easily shared with those who need to know.

4.2 This document sets out the processes involved in creating and maintaining digital care and support plans.

Background and definition

4.3 Care and support planning is a defined process which helps people to set their own aims, and then secures the support and care that is needed to achieve them. It is the key that unlocks person centred, coordinated care. It is about working with a care and support partner[6] to think about:

- what is important to you,
- things you can do to live well and stay well,
- what care and support you might need from others (National Voices[7]).

4.4 The Care Act guidance states "the plan should be person centred, with an emphasis on the person having every reasonable opportunity to be involved in the planning to the extent that they choose and able".[8]

4.5 Care and support planning is carried out with the consent of the person. Where the person does not have capacity to consent to the arrangements the process should always be carried out in the best interests of the person, with input from their family/carer if possible.

4.6 The care and support planning conversation provides an opportunity to empower the person to take an active role in their care. The role of the personalised care and support plan is to record the decisions agreed, during this conversation, with the person.

4.7 The purpose of a digital care and support plan is to support multi-provider (or multidisciplinary) person-centred care, by enabling plans to be shared digitally, ensuring that an up-to-date plan is available immediately whenever and wherever it is needed.

4.8 In addition to care and support plans, some people also have plans which set out what should and should not be done if their health or wellbeing gets worse or if they have a crisis. These are often known as contingency, crisis or anticipatory plans.

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[6] The professional or supporter you work with could be a doctor, nurse or social worker, another professional or someone from a support organisation.

[7] https://www.nationalvoices.org.uk/

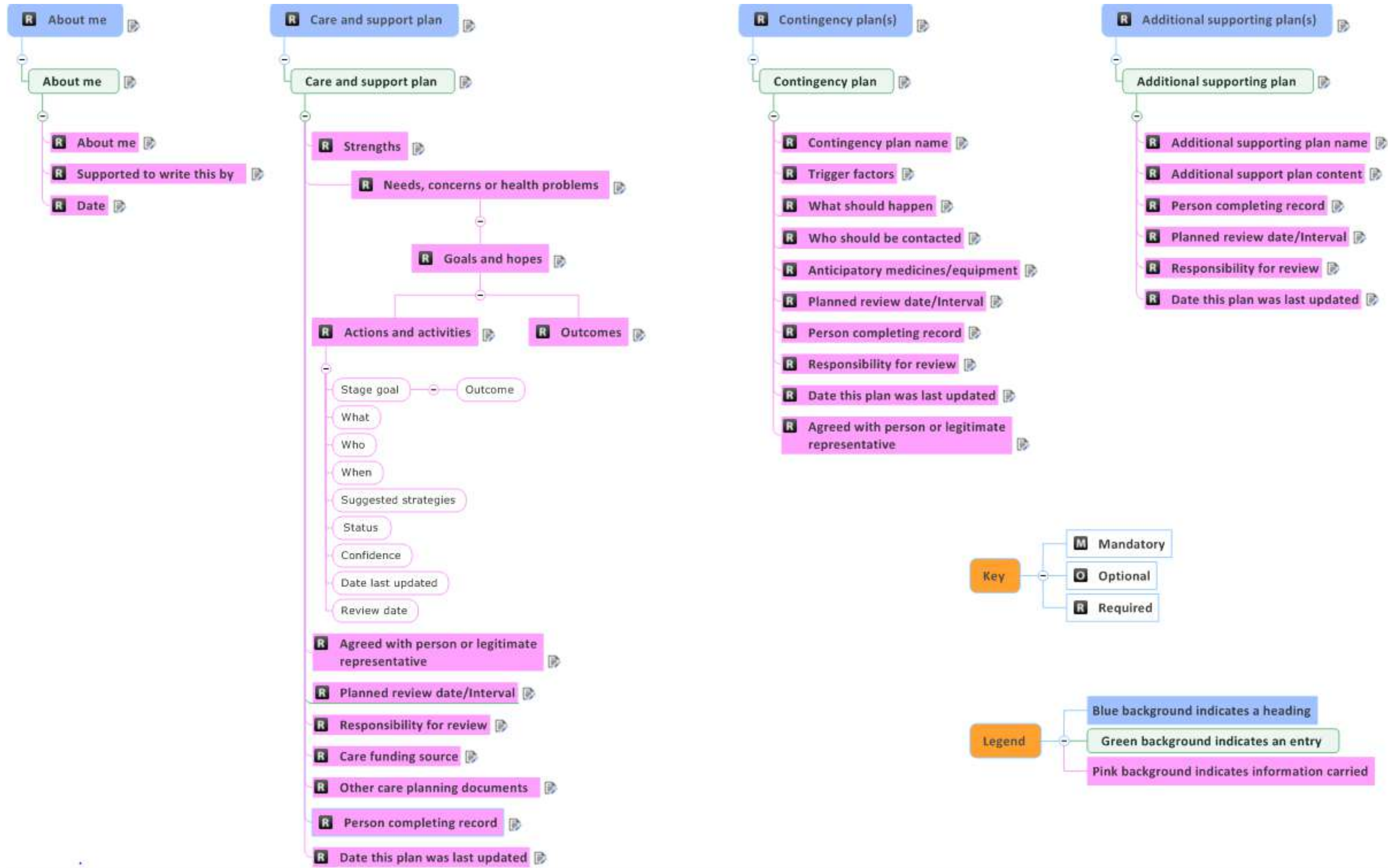
[8] https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#person-centred-care-and-support-planning

4.9 Some people also have a plan which set out their wishes and preferences for care should they lack the capacity to articulate these wishes in an emergency situation. They are developed through a process that creates personalised recommendations for a person's clinical care in a future emergency in which they are unable to make or express choices. They are often used by and for people approaching the end of life. The purpose of the plan is to provide health and care professionals responding to that emergency with a summary of recommendations to help them to make immediate decisions about that person's care and treatment. A process for emergency planning which is known as ReSPECT[9] was developed by the Resuscitation Council (UK)[10] and other organisations.

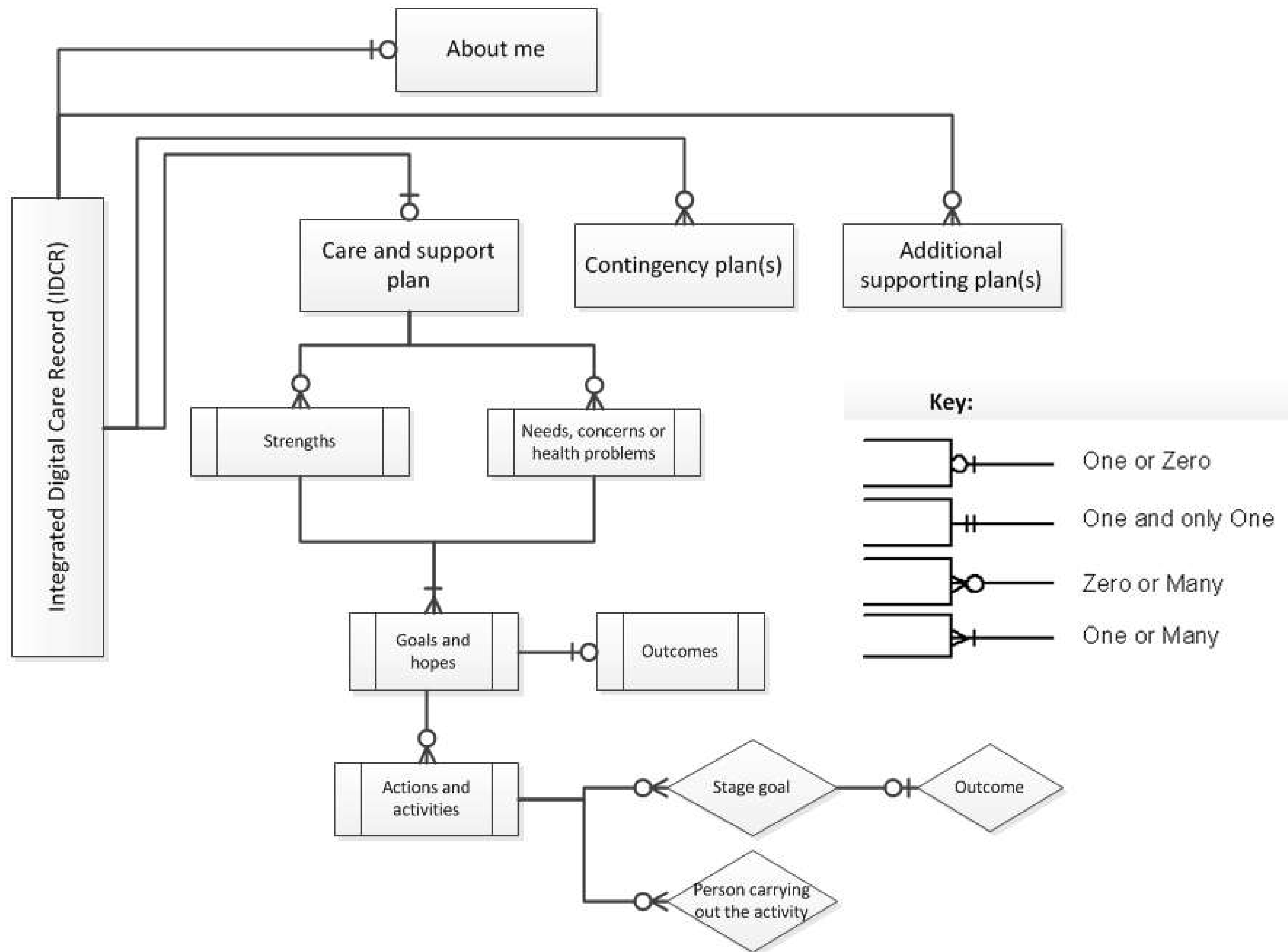
[9] http://www.respectprocess.org.uk/
[10] https://www.resus.org.uk/

Content

4.10 The structure of the care and support plan headings and additional documents is as follows (*see section 5 for details*):



4.11 The relationship between the different plans and main record sections is illustrated in the following diagram:



Scope of use

4.12 A care and support plan is relevant to anyone with a health condition requiring long-term ongoing personalised care and support.

4.13 It should be an integral part of an individual's integrated health and care record and include relevant information e.g. personal demographics, relevant contacts, etc. without needing to re-enter this information again in the care and support plan.

4.14 Other information from the individual's care record may be needed to inform and monitor the integrated care and support plan such as medications, allergies, test results etc. These have not been included as new headings in the care and support plan as they would already be part of the wider record and the expectation is that systems will be able to combine this information with the care and support plan as needed.

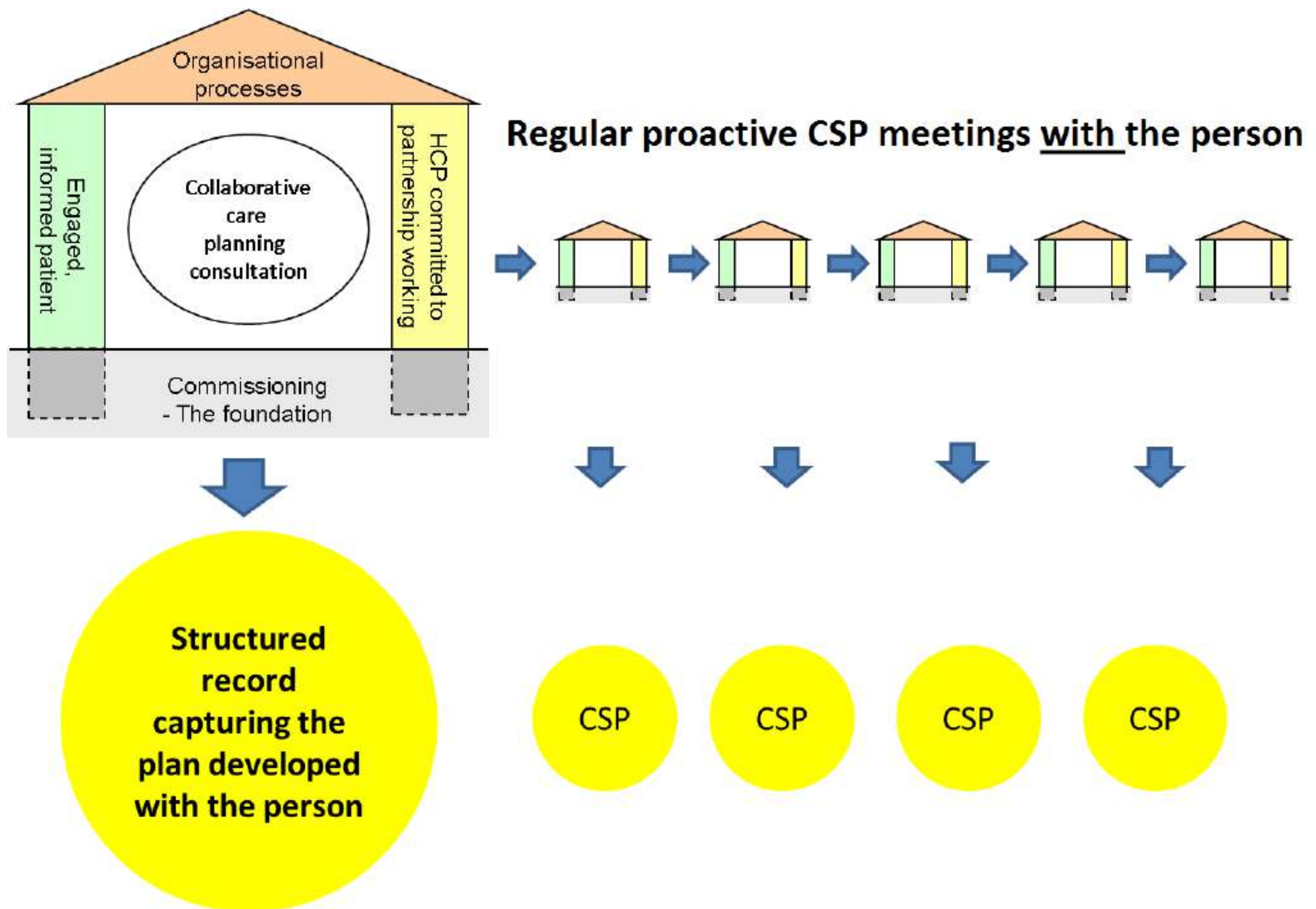
4.15 The scope of this project excludes:

- Standards for use case or condition specific care plan content e.g. diabetes or end of life care, although examples will be provided to illustrate how the proposed standard care and support plan could be used by people with different conditions.
- Care plans used by individual disciplines or services to manage specific aspects of care (e.g. hospital hip fracture care pathway or plan, district nursing wound management care plan).
- Care and support plans set up by individuals to manage their own social care, where these do not have any health care input.
- Financial assessments, personal budgets and allocation of resources.
- Care plans for children and young people.

4.16 Requirements for additional functionality may be identified once interoperable digital care and support plans are being used by multidisciplinary teams, e.g. workflow functions, notifying others (e.g. care team members, carer) when a care plan is updated, but requirements for this are yet to be established. Experience of using integrated digital care and support plans in practice will help to define these.

Process

4.17 The House of Care[11] framework for long term conditions can be used to illustrate a care and support planning process:



4.18 Care and support planning is a process directed by the individual in which other people may be needed to help with developing and delivering. It is developed / adapted progressively over time and owned by the individual.

4.19 The documentation of the care planning process is the care and support plan. It is owned by the individual and shared with others with consent.

4.20 Supporting actions may be added by other professionals, if agreed with the person, to support them to achieve their goals.

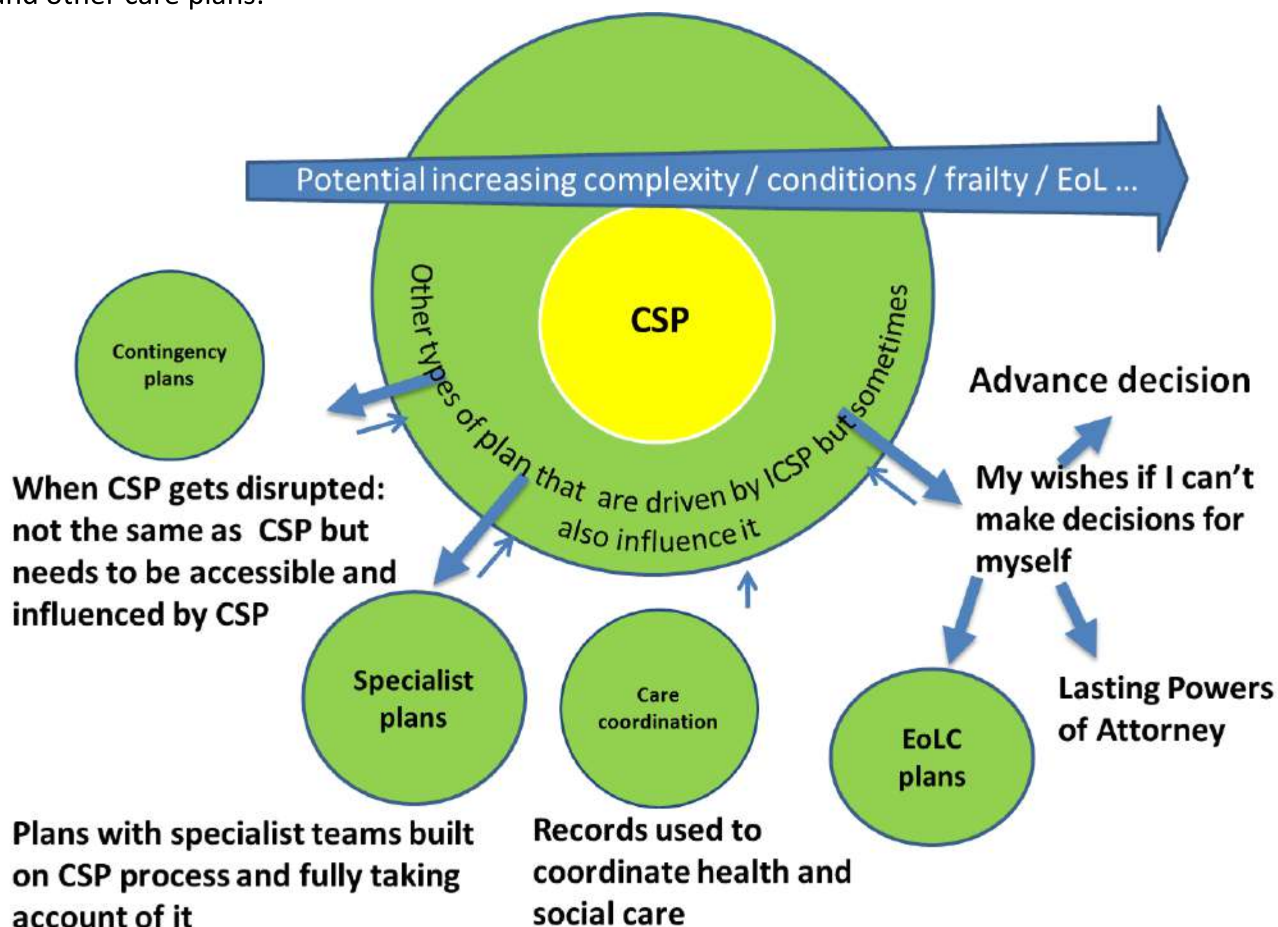
[11] https://www.england.nhs.uk/ourwork/ltc-op-eolc/ltc-eolc/house-of-care/

Care planning context

4.21 Care and support planning is a defined process which helps people set their own aims, and objectives. It helps to identify their strengths and assets, and the support that they need to achieve them.

4.22 The care and support plan should demonstrate how the person's aims and goals will be met.

4.23 The figure[12] below illustrates an example of the relationship between a care and support plan and other care plans.



4.24 A person may accumulate multiple **specialist care plans** as the complexity of their health needs increases with time.

4.25 These plans may help other people involved in a person's care to work in a co-ordinated way and may document detailed specialist input.

4.26 Specialist care plans are often focused on a specific condition or need, and may be developed in consultation with an individual by a professional, service or team. They do not necessarily form part of the care and support plan (CSP) but should be directed by the CSP and may inform it.

[12] Thanks to Nick Lewis-Barned and the Year of Care programme.

4.27 **Contingency plans** are for those people who have specific and predictable risks associated with their health and wellbeing. They will include foreseeable triggers, actions and people to contact should the person's health or other circumstances get worse. They address circumstances when the CSP is disrupted. They are not the same as the CSP but should be informed by it.

4.28 **A record to support care coordination**. Detailed care records may need to be shared between health and social care to support some individuals requiring multi-agency support. They are used to coordinate care and may include plans and schedules of care, and detailed care records.

4.29 **End of Life Care Plan** will only be required when a person is in the later stages of illness and where there is an identified need for one. It includes information related to wishes and views about end of life care, including preferred place of care, as well as the individual's views about any interventions, treatments and whether or not cardiopulmonary resuscitation is appropriate or wanted. Advance care plans, statements and directives may be produced by a person which enable the person to make decisions regarding future care which are taken into account in an end of life care plan, should they lack capacity. These may change as a person's aims and objectives change throughout the care pathway, and should be regularly reviewed with the individual. A person may also appoint someone to be a lasting power of attorney for personal welfare to make decisions on their behalf should they lack capacity.

4.30 Some plans have already been produced by the PRSB in previous projects, their relationship to CSPs is described below:

Plan and requested actions is a heading included in transfers of care such as discharge summaries and outpatient letters, to make clear who is expected to take responsibility for actions following transfer of care, e.g. the hospital, patient or GP. It may also include information about whether the patient or legitimate representative has agreed the entire plan or individual aspects of treatment, expected outcomes, risks and alternative treatments; and other instructions and arrangements. This type of plan is an additional supporting plan.

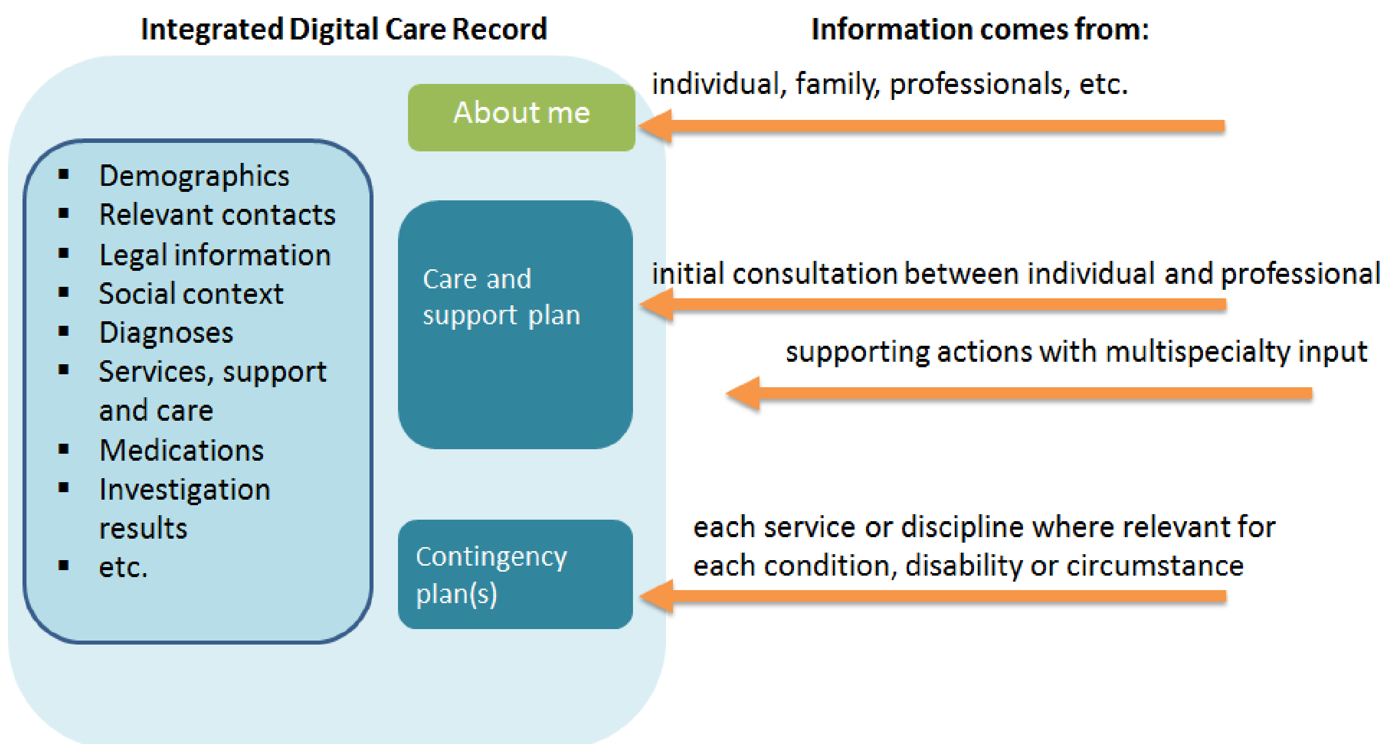
Crisis Care Plan (as part of PRSB Crisis Care Summary, 2017) [13] includes headings for a plan to be available in a crisis situation. It includes end of life elements that may not be applicable to include in a more generic contingency plan. Several of the previous headings in Crisis Care Summary that relate to contingency planning may require updating in future revisions to align with the current headings for a contingency plan.

[13] *Crisis care summary standard*. *PRSB*. https://theprsb.org/publications/crisis-care-standard

4.31 All of the plans described in this section need to be available to the person and to those providing care and support (with the consent of the individual). The plans should be made available as part of an integrated digital care record (IDCR).

4.32 The care and support plan is a digital record which is intended to be used to support a person's care rather than individual service or specialist professional's needs. The record should be available across disciplines and different providers. It should support integrated communication and care packages so that referrals between different professionals can be mapped and any advice, recommendations or treatment plans can be supported by all those who see the individual.

4.33 The care and support plan includes the person's priorities at the time and is not a detailed record of the person's care needs. It should not be confused with the person's integrated digital care record which will hold the demographic and care delivery information. The way in which the care and support plan and other plans fit within the IDCR is set out in the diagram below.



About me

4.34 'About me' is essential information that should be completed by the person themselves or, in some cases, by those who know the person best. It has similarities to the concept of 'care/hospital passports', (which are owned by the individual, predominantly paper sometimes apps or wiki's), but further work would be required to elucidate this.

4.35 'About me' provides information that an individual considers important to communicate to those providing care and support. This includes an individual's preferences for how they receive care and support in a person-centred approach. It could also include information on the individual's strengths to provide a basis for building upon personal and community assets to enable self-care where possible.

4.36 'About me' should be the information that is first viewed in a care record as it includes important information about the person relevant to all care and support providers. Ideally this information is also available in a multimedia format e.g. video, particularly when a person has problems expressing themselves. It should be possible to update the 'about me' information whenever the individual wishes to do so.

4.37 It should be possible to store a history of applied changes and access previous versions of this information after any changes are made.

4.38 'About me' may be structured to assist the person completing as well as to make it easier to follow for the professional reading the document. However, structure is not mandatory and the information which goes in here depends on what is important to the individual[14]. As an example, it could include:

Example 1	
	a) *Preferred name* b) *Communication needs and how people should communicate with me* c) *Core values/spiritual beliefs as they relate to my care* d) *Important things about my daily or weekly routine* e) *How I express pain or anxiety* f) *Any important information about sleep* g) *Food preferences and diet* h) *Likes, dislikes and interests* i) *Preferences, concerns and wishes* j) *Carer's concerns and wishes* k) *Any information about the way I behave, things which I might find difficult or upsetting, things which help me relax* l) *Health beliefs, e.g. attitude to exercise, concerns, expectation and*

[14] For additional examples, see *Personalised care & support planning. Think Local Act Personal.* www.thinklocalactpersonal.org.uk/personalised-care-and-support-planning-tool/

	knowledge of health conditions, how I take my medications. *m) Current strengths and supporting factors that may help to self-manage my health and well being*
Example 2	*a) My background* *b) My family, friends and others who are important to me* *c) How I like to spend my time (work, hobbies and interests)* *d) My beliefs (including religion)* *e) My health, things that affect how I would like my health and social care needs met (diet, feelings about medication, how I take it)* *f) Things that make me happy when people are supporting me* *g) Things that make me sad when people are supporting me* *h) Things that make me annoyed when people are supporting me*

4.39 Some information may be retrieved from other parts of the care record to avoid duplication, e.g. information included under heading 'Person concerns, expectations and wishes' (previously developed by PRSB) should be included in the 'about me' section.

Creation

4.40 Care and support planning is part of planned systematic care and support. It should be possible for a care and support plan to be created at any time, but once in place it will need to be subject to regular reviews as part of a planned process.

4.41 It should also be possible for a care professional from any care setting (primary, secondary, mental health, community, social care), as well as family/carers to support an individual in creating a care and support plan.

4.42 It should be possible for a care and support plan to be recorded by an individual and/or a health or care professional.

4.43 The plan is owned by the individual, and so it should be possible to restrict access to the care and support plan, based on the individual's consent preferences.

4.44 It should be possible to add attachments or hyper-links in care and support plans to provide guidance, learning materials, explanatory notes, etc.

4.45 It should be possible to include tables (e.g. weekly schedule), diagrams or images (e.g. to illustrate how a person has made progress towards a goal) as well as video and audio clips (i.e. as a communication tool for individuals with complex accessibility requirements).

4.46 It should be possible to prioritise goals, indicating the importance of each goal to the person (e.g. a scale 1 to 10).

4.47 Each action may also have an associated additional indicator showing how confident the person is to carry it out (e.g. a scale from 1 to 10).

4.48 The care and support plan should be structured in a way that supports digital information exchange, with separate coded headings for strengths, needs and problems which can be linked to specific goals. Each goal will link to specific actions associated with it. Goals may also have related outcomes.

4.49 Agreement of the plan with the person (or representative) should be recorded. If agreement cannot be obtained the reason for this should be documented.

4.50 Where a person has been unable to agree, due to, for example, lacking mental capacity, actions should be undertaken to maximise capacity and the plan should demonstrate how a person's rights will be promoted. If a person is unable to consent, a mental capacity assessment should be attempted, and if there is no legal representative a best interest decision made.

4.51 In health and social care there may be different sources of funding (e.g. personal budget) to meet the aims and goals of the person. The 'Care Funding Source' heading should only detail the source of the funding so as to support easy resolution where a question about funding arises. The information should not include the details of the funding, which will be held in separate documents.

4.52 Where a care and support plan has been created, the individual may wish to notify others of its existence. There are various ways in which this could be done, and this functionality is out of scope of this project.

Viewing and Updating

4.53 The individual and health and care professionals from any care setting who are involved in the person's care and support should be able to view an individual's care and support plan online, subject to the individual's consent.

4.54 It should be possible to have multiple ways to view the care and support plan, by including or excluding particular details. This should depend on who is accessing the CSP and the information that is most relevant to them, e.g. it may be more important for ambulance services to see the contingency plan over the CSP.

4.55 It should be possible to view and update the integrated digital care and support plan in real time when there is an interaction/conversation with the person or when the person wants to update it.

4.56 Where possible, the headings associated with goals and actions that are the focus of specific care professionals should be interoperable with the care plan that that professional uses for their day to day work.

4.57 It should be possible to add comments to the plan and to sections in the plan, e.g. to identify progress towards a goal, to comment on actions undertaken or suggest changes to actions. Note that adding comments to a plan is not the same as having a dialogue with others involved in the care and support planning process. Separate functionality, e.g. secure messaging would be required for this.

4.58 The integrated digital care and support plan will be reviewed as a whole at a regular, scheduled review meeting with the individual.

4.59 When an integrated care and support plan is updated, it should be saved as a new version, but the previous versions must be retained as part of the individual's care record. The individual updating it should be identified and the date/time of the update.

4.60 If the structure of the care and support plan allows, updates may include:

- Add, edit or archive strengths, needs, issues or problems. If a strength/need/issue becomes more or less important, then goals may need to be changed, as will associated actions.
- Add, edit or archive goals. When a goal is archived it should be possible to also archive the actions associated with it. If the actions are still valid it should be possible to attach them to another goal.
- Add, edit or archive actions. Once an action has been completed (i.e. status updated to indicate it has been completed), it should be possible to archive it from the care and support plan. It should be removed from the current active view of the plan, but available to view in previous versions of the plan.
- Record outcomes related to goals. Once a goal has been achieved, it should be possible to archive it from the care and support plan, so that it is removed from the view of the current plan, but available to view in previous versions of the care and support plan.

Ending

4.61 The digital care and support plan may be ended when, for example, the plan is no longer applicable, the person wants it to be ended or if the person is deceased.

4.62 In all of these cases the plan should be made dormant or inactive, i.e. no further updates can be made, but the care and support plan should be retained as part of the individual's record.

4.63 When a care and support plan is ended, all those involved in the person's health and care should be notified.

Contingency plans

4.64 Not everyone who has a care and support plan will need a contingency (also known as crisis) plan.

4.65 This plan is for those people who have specific and predictable risks associated with their health and wellbeing. It describes how disruptions to the care and support plan should be addressed.

4.66 There may be a number of different contingency plans to manage different aspects of health and wellbeing, e.g. diabetes, respiratory, mental health, substance misuse, etc. The plan may cover different scenarios, e.g. mild disruption/issues, through to more severe.

4.67 It must be possible to create a contingency plan at any time when the individual and those providing care and support identify a need for such a plan.

4.68 Contingency plans may include end of life care planning elements. These may form part of an initial conversation but a full end of life care plan should also be included where appropriate.

4.69 It should be possible to:

- Add, edit or archive the whole plan. If a plan is archived it will remain dormant until such time as it needs to be reactivated. It should be possible to use the content of the dormant plan to create a new plan.
- Add, edit or archive any of the individual actions, people to contact or anticipatory medicines and equipment. Each time the plan is updated a previous version of the plan is retained and a newer version created.

Additional supporting plans

4.70 It must be possible to hold additional supporting plans, which may be linked to the care and support plan where the individual or care professional decides that the information should be available to others. Examples of additional supporting plans include: The Asthma UK action plan, specialist components of a mental health plan that cannot be incorporated into the headings of this standard, tissue viability plans, nutrition plans, a falls prevention plan, hospital or other service transfer of care plan, etc.

4.71 The format of additional supporting plans will vary according to the type of plan. Some may be structured and coded, others may include diagrams or images.

4.72 Additional supporting plans should be available for others to view, but will only be created, updated and ended by the service creating the plan.

4.73 When an additional supporting plan is updated a new version of the plan may be linked to the care and support plan, again at the discretion of the individual or care professional.

Glossary

4.74 A review of existing care and support plans and the feedback from the survey identified many different names for each section of the care and support plan. A non-exhaustive example list of these is included in the table below, to support local mapping to the structures defined for a generic care and support plan.

Heading	Alternative names
About me	○ This is me ○ All about me ○ What is essential to know about me ○ Person's Views (in their words) ○ About me and my life ○ About me in the context of my life ○ About my care ○ About my health and wellbeing ○ My care record ○ My health ○ My preferences ○ My story / my life ○ Things in my best interest ○ Things you should know about me ○ What I like ○ What is important to me and my health ○ What matters to me ○ What you need to know about me
Care and Support Plan	○ Action Plan ○ Care and Personal Support Plan ○ Care Delivery Plan

	○ Care, Support And Treatment Plan ○ Health and Social Care Management Plan ○ Health and Wellbeing Care And Support Plan ○ Individual Support Plan ○ My Goals and Plans ○ My Plan of Care And Support ○ My Recovery Plan ○ Recovery Plan ○ Rehabilitation Plan
Goals	○ Goals of care ○ Goals, aspirations or wishes ○ What I want to achieve ○ Desired outcome
Actions	○ Activities ○ Proposed care and support
Outcomes	○ Meeting goals set ○ My desired outcomes ○ Review ○ What that looks like
Contingency plan	○ Anticipatory Care Plan ○ Back-up plan ○ Contingency plan ○ Contingency steps ○ Emergency action plan ○ Emergency plan ○ Future planning or decisions ○ If all else fails ○ If something goes wrong ○ Just in case ○ My crisis care plan ○ My safety plan ○ Plan of action ○ Plans for an emergency ○ Plans for unforeseen events ○ Safety net ○ Step up plan ○ Urgent Action Plan ○ What should happen if things go wrong ○ What to do if things are not going well ○ What to do if things get suddenly worse ○ What to do in an emergency
Trigger factors	○ What might go wrong
What should happen	○ Suggested actions
Anticipatory medicines/ equipment	○ What I might need

Wider context

4.75 Other information will be needed to support the creation, delivery and monitoring of a care and support plan.

4.76 This information may be taken from existing electronic health and care records. It should be possible to bring other information from the care record into the care and support planning process so that it is easily accessible, either within or beside the care and support plan, without having to navigate around the record to find it. For example, it may be included in a 'care planning view'.

5. Information models

Detailed information models are defined in separate documents. Please see the PRSB website at https://theprsb.org/standards/dcsp/

6. Appendix A – Literature review

Terms searched:

Integrated care plans
Integrated care planning
Integrated health and social care plan
Guidance related to integrated care planning
Integrated care planning standards and good practice
Structure and content of an integrated care plan
Structure of an integrated care plan
Content of an integrated care plan
Generic integrated care plan
Integrated care plan
Generic integrated care planning
Palliative care plans
End of life care plans
Diabetes care plans
Shared care plans
Shared care planning
Integrated care for older patients
Care planning integration
Generic care plan
Care plan structure
Integrated health care plan
Integrated patient care planning
International standards for integrated care plans

A. Casas, T. Troosters, J. Garcia-Aymerich, J. Roca, C. Hernández, A. Alonso, F. del Pozo, P. de Toledo, J. M. Antó, R. Rodríguez-Roisín, M. Decramer. Integrated care prevents hospitalisations for exacerbations in COPD patients. European Respiratory Journal 2006 28: 123-130 (http://erj.ersjournals.com/content/28/1/123.short)

Coulter A, Entwistle VA, Eccles A, Ryan S, Shepperd S, Perera R. Personalised care planning for adults with chronic or long-term health conditions. Cochrane Database of Systematic Reviews 2015, Issue 3. Art. No.: CD010523. DOI: 10.1002/14651858.CD010523.pub2 (http://www.cochrane.org/CD010523/COMMUN_effects-of-personalised-care-planning-for-people-with-long-term-conditions)

Craig C. Earle, From the Division of Population Sciences, Department of Medical Oncology, Dana-Farber Cancer Institute, Boston, MA. Failing to Plan Is Planning to Fail: Improving the Quality of Care With Survivorship Care Plans. DOI: 10.1200/JCO.2006.06.5284 Journal of Clinical Oncology 24, no. 32 (November 2006) 5112-5116. (http://ascopubs.org/doi/abs/10.1200/JCO.2006.06.5284)

Dahm, M. F. and Wadensten, B. (2008), Nurses' experiences of and opinions about using standardised care plans in electronic health records – a questionnaire study. Journal of Clinical Nursing, 17: 2137–2145. doi:10.1111/j.1365-2702.2008.02377.x (http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2702.2008.02377.x/full)

EN ISO 13940:2016 Health informatics – System of concepts to support continuity of care. European Committee for Standardization. 27 January 2016. (https://contsys.org)

FHIR care plan. FHIR Release 3 (STU; v3.0.1-11917). HL7.org 2011+. (https://www.hl7.org/fhir/careplan.html)

Lee, T.-T. and Chang, P.-C. (2004), Standardized care plans: experiences of nurses in Taiwan. Journal of Clinical Nursing, 13: 33–40. doi: 10.1111/j.1365-2702.2004.00818.x (http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2702.2004.00818.x/full)

Murphy A W, Cupples M E, Smith S M, Byrne M, Byrne M C, Newell J et al. Effect of tailored practice and patient care plans on secondary prevention of heart disease in general practice: cluster randomised controlled trial BMJ 2009; 339 :b4220 (http://www.bmj.com/content/339/bmj.b4220)

NHS Digital (2017). Using SNOMED CT in health and social care for care planning (https://isd.digital.nhs.uk/trud3/user/guest/group/0/pack/17/subpack/41/releases)

Timothy D Shortus, Suzanne H McKenzie, Lynn A Kemp, Judith G Proudfoot and Mark F Harris. Multidisciplinary care plans for diabetes: how are they used? Med J Aust 2007; 187 (2): 78-81. (https://www.mja.com.au/journal/2007/187/2/multidisciplinary-care-plans-diabetes-how-are-they-used)

Zwar, N., Hermiz, O., Comino, E., Shortus, T., Burns, J., & Harris, M. (2007). Do multidisciplinary care plans result in better care for patients with type 2 diabetes? Australian Family Physician, 36(1), 85-9. (http://search.proquest.com/docview/216296243?pq-origsite=gscholar)

7. Appendix B – Example use cases

Example use cases are provided below to illustrate how the headings can be used to accommodate different styles of plans and can be used by people with different health and wellbeing strengths, needs and problems. They illustrate use by people with multiple long-term conditions, mental health issues, learning disabilities and complex health conditions. Examples of how the about me, contingency plan and emergency plan headings can be used are also provided.

Please note the examples provided are strictly for illustration purposes (i.e. to show how information can be recorded using the headings in different care settings) and are not intended as exemplars of the way in which care plans should be ordered and sequenced.

Each example comprises two stages that illustrate the on-going development of the digital care and support plan, with multi-disciplinary team or multiple care provider input. The first stage is initiation – when a care and support plan is first created. This action may include referrals to other professionals. The second stage is a later point in time when another professional adds information to the plan with onward actions. Within this document, the second stage is indicated in a yellow shade. '*Myself*' in each example refers to the person the care and support plan is owned by, and should include their name and contact details.

7.1. Example 1

Patient demographics		**Relevant contacts**		
Patient name	Ms Jane Doe	*Name*	*Relationship / role*	*Contact details*
Date of birth	01/01/1960	Tom Smith	Care-coordinator	tom.smith5@nhs.net
Gender	Female	Richard Doe	Husband	077 899 888
NHS number	123456789	Lisa Lowe	Daughter	079 999 999
Hospital ID	HN98765	Tom Robbins	Physiotherapist	t.robbins@nhs.net
Patient address	46 Birch Close AG2 6SL	Dr Jane Collins	COPD specialist	jane.Collins2@nhs.net
Patient email address		Janet Moss	Pharmacist	j.moss@nhs.net
Patient telephone number.	077 7777 777	Sandra Laing	Occupational Therapist	s.laing@nhs.net
GP Practice details		***Social context***		
GP practice identifier	ASDF7789	*Services and care*	Main Hospital NHS, 30 High Rd, AG1 8SD	
GP name	Dr Joe Collins		Community Health NHS, 56 High Rd, AG1 3JL	
GP details	U Health Centre, 12 High Road, AG1 2RD, (01234) 956412		Specialist service NHS, 72 Round Lane, AG2 3YA	

The above information with any additional records (e.g. diagnoses, investigation results) would also be used to inform care and support planning.

About me	Supported to write this by	Date
I am 78 and I live with my husband. I enjoy looking after my grandchildren. I would like to do more with them but get pains from arthritis. I also have diabetes and COPD.	Myself (Ms Jane Doe) Dr Joe Collins, GP, joe.Collins9@nhs.net	17.10.17

The care and support plan in example 1 includes two goals initially agreed between a GP and the person. One of the goals: *'to walk to the park with my grandchildren'* initially included one action for the GP to make a referral to a physiotherapist. The care and support plan illustrates how after the appointment in one month's time, the physiotherapist has agreed and added a stage goal related to the overall goal. There is also a related action as well as suggested strategies and the person has identified that on a scale of 1 to 10, their confidence is at 7 to carry out the action. When this stage goal was fully achieved, a new stage goal was agreed. At the next review, status of each action and outcomes of goals will be further updated.

This person also has an additional COPD action plan attached to the care and support plan.

Needs, concerns or health problems	**Goals**	**Stage goal**	**Actions**		**Outcomes**	**Person completing record**
Would like to lose weight	To fit into size 16 dress by Christmas **Importance:** 10/10		Increase walking. Cut out daily biscuits with morning and afternoon coffee. Change sugar to sweeteners in hot drinks.	**Who:** Myself **When:** Between now and Christmas **Status:** Not started **Date:** 17.10.17 **Planned review date:** 6 months		**Name:** Dr Joe Collins **Role:** GP **Contact:** 020 345 6789, joe.Collins9@nhs.net **Organisation:** Surgery
Pain in knees	To walk to the park with my grandchildren **Importance:** 10/10		Gradually increase walking distance, see physiotherapist	**Who:** Myself/ physiotherapist **When:** Over 6 months **Status:** Started **Date:** 17.10.17 **Planned review date:** 6 months	On-going	**Name:** Dr Joe Collins **Role:** GP **Contact:** 020 345 6789, joe.Collins9@nhs.net **Organisation:** Surgery
		To walk to the end of the garden **Outcome:** Fully achieved	To do home exercise programme as given by the physiotherapist. 10 repeats of each exercise x2 daily	**Who:** Myself **When:** Until end of May **Suggested strategies:** Slowly increase walking distance each week		**Name:** Tom Robbins **Role:** Physiotherapist **Contact:** 020 345 6789, t.robbins@nhs.net **Organisation:** NHS Trust

		24.11.17		**Status:** Completed **Confidence:** 7/10 **Date:** 10.11.17		
		To walk to the end of the street	Continue home exercise program. 15 repeats of each exercise x3 daily	**Who:** Myself **When:** Until end of May **Date:** 24.11.17		
			Physio review	**Who:** Physiotherapist **When:** At end of May **Status:** Not started **Date:** 10.11.17 **Planned review date:** 6 months		**Name:** Tom Robbins **Role:** Physiotherapist **Contact:** 020 345 6789, t.robbins@nhs.net **Organisation:** NHS Trust

Planned review date/interval	Responsibility for review	Agreed with person	Date this plan was last updated	Last updated by
In 6 months	**Name:** Dr Joe Collins **Role:** GP **Contact:** 020 345 6789, joe.Collins9@nhs.net **Organisation:** Surgery	Yes	10.11.17	**Name:** Tom Robbins **Role:** Physiotherapist **Contact:** 020 345 6789, t.robbins@nhs.net **Organisation:** NHS Trust

Other care planning documents	Date
COPD action plan	17.10.17

Contingency plan

Plan name	Trigger factors	What should happen	Who should be contacted	Anticipatory medicines/ equipment	Agreed with person	Person completing record	Date this plan was last updated	Planned review date	Responsibility for review
COPD contingency plan	Chest infection/ exacerbation COPD	Follow advice on COPD action plan. Start rescue pack if indicated.	Urgent Care Team 01915555555 or Glenpark Surgery on 019122222222	Amoxicillin 500mg tds and Prednisolone 30mg daily as per rescue pack plan	Yes	**Name:** Dr Joe Collins **Role:** GP **Contact:** 020 345 6789, joe.Collins9@nhs.net **Organisation:** Surgery	17.10.17	19.04.17	**Name:** Dr Joe Collins **Role:** GP **Contact:** 020 345 6789, joe.Collins9@nhs.net **Organisation:** Surgery

7.2. Example 2

Example 2 includes a care and support plan developed in agreement between GP and the person. On a separate appointment, the GP has worked with the person to add additional information to their 'about me' section on how the person takes their medication. The person felt this was important to note and communicate.

Importance of each goal, confidence of carrying out each action and suggested strategies are included in the care and support plan. Goals and actions will be updated at the next review.

A contingency plan for COPD was developed by another specialist on a previous occasion.

About me	Supported to write this by	Date
My 45 year old son died before Christmas last year and I still feel sad. I get very down at that time of year I like to be straight with people and for people to explain things properly I have breathing problems and diabetes My wife gets worried about my health	Myself	17.10.17
How I take my medication: Metformin, 500mg, For diabetes. One capsule three times daily with food Atorvastatin, 20mg for Cholesterol. At night.	Myself; Dr Joe Collins, GP, joe.Collins9@nhs.net	26.10.17

Care and support plan

Needs	Goals	Actions		Outcomes	Person completing record
Improve my breathing	Increase my activity **Importance:** 8/10	Go to the rehab group again	**Who:** GP referral **When:** In the next month **Suggested strategies:** Go just to the exercise bit of the rehab group **Status:** Not started **Confidence:** 7/10 **Date:** 17.10.17 **Planned review date:** 17.11.17		**Name:** Dr Joe Collins **Role:** GP **Contact:** 020 345 6789, joe.Collins9@nhs.net **Organisation:** Surgery
Weight issues	Lose weight **Importance:** 5/10	Halve my wine intake	**Who:** Myself **When:** 12 lbs in 3 months **Suggested strategies:** Halve wine intake to ½ a bottle at a time instead of a full bottle **Status:** Not started **Confidence:** 8/10 **Date:** 17.10.17 **Planned review date:** 17.11.17		**Name:** Dr Joe Collins **Role:** GP **Contact:** 020 345 6789, joe.Collins9@nhs.net **Organisation:** Surgery

Planned review date/interval	Responsibility for review	Date this plan was last updated	Updated by
17.11.17	**Name:** Dr Joe Collins **Role:** GP **Contact:** 020 345 6789, joe.Collins9@nhs.net **Organisation:** NHS Trust	17.10.17	**Name:** Dr Joe Collins **Role:** GP **Contact:** 020 345 6789, joe.Collins9@nhs.net **Organisation:** Surgery

Contingency plan

Plan name	Trigger factors	What should happen	Who should be contacted	Anticipatory medicines/ equipment	Agreed with person	Person completing record	Date this plan was last updated	Planned review date	Responsibility for review
COPD plan	Coughing and breathing worse Green phlegm	Use my rescue medication early and don't put off like last time	Liz 0777589857 if no improvement in symptoms	Rescue pack at home	Yes	**Name:** Dr Jane Collins **Role:** COPD specialist **Contact:** 020 345 6789, jane.Collins2@nhs.net **Organisation:** NHS Trust	08.08.17	In 6 months	**Name:** Dr Jane Collins **Role:** COPD specialist **Contact:** 020 345 6789, jane.Collins2@nhs.net **Organisation:** NHS Trust

7.3. Example 3

The care and support plan in example 3 was initially agreed in a care planning session six months prior to the illustrated example and had one goal related to '*getting out more*' with two actions assigned to the person themselves. During a review with the GP, the person discussed their progress and the goal was marked as fully achieved. It has now been archived from the main care and support plan view but is still accessible in the appendix. One new concern 'feeling unfit' and an associated goal were agreed by the person and their GP at the consultation.

About me	Supported to write this by	Date
I moved to the area from Cumbria I don't know anyone in the area My husband recently had a heart attack I have diabetes and heart disease	Myself	17.05.17

Care and support plan

Needs, concerns or health problems	Goals	Actions		Outcomes	Person completing record
Feeling unfit	Lose 6 lbs in weight in 6 weeks and keep it off **Importance:** 9/10	Join Slimming World	**Who:** Myself **When:** Next week **Suggested strategies: Status:** Not started **Confidence:** 7/10 **Date:** 18.11.17 **Planned review date:** 25.04.18		**Name:** Dr Kate Atkins **Role:** GP **Contact:** 020 345 6789, k.atkins@nhs.net **Organisation:** Surgery

Appendix – archived items removed from the main care and support plan view

Needs, concerns or health problems	Goals	Actions		Outcomes	Person completing record
Feeling lonely	Getting out more **Importance:** 10/10	Look into local WI and Woman's Guild groups and join	**Who:** Myself **When:** This week **Suggested strategies:** Getting out at least 3 times a week **Status:** Completed **Confidence:** 9/10 **Date:** 17.05.17 **Planned review date:** 18.11.17	Fully achieved. 18.11.17 **Comment:** Feeling better and getting out regularly; joined local groups	**Name:** Dr Joe Collins **Role:** GP **Contact:** 020 345 6789, joe.Collins9@nhs.net **Organisation:** Surgery
		Talk to my husband about how I feel about having to be in all of the time	**Who:** Myself **When:** This week **Status:** Completed **Date:** 17.05.17 **Planned review date:** 18.11.17		

Planned review date/interval	Responsibility for review	Agreed with person	Date this plan was last updated	Updated by
In 6 months	Dr Kate Atkins, GP, NHS Trust	Yes	18.11.17	**Name:** Dr Kate Atkins **Role:** GP **Contact:** 020 345 6789, k.atkins@nhs.net **Organisation:** Surgery

7.4. Example 4

Example 4 includes an initial plan as agreed between the person and their care-coordinator during a Care Programme Approach (CPA) meeting. Several actions were followed up by the patient and these were indicated as completed. Additional actions were then added by a physiotherapist, consultant psychiatrist and a pharmacist a couple of weeks later – these all relate to what was previously agreed and now include further input from these specialists.

About me	Supported to write this by	Date
What recovery means to me? My long term goals! What I would like to achieve in 12 months' time… Return to work as a teacher, redecorate my bedroom and enjoy eating again. **What matters to me** Feeling safe, having friends and being useful **My skills, strengths and experiences that will help me achieving my goals** I am a teacher, I love children. I have been through a lot and can help them. I enjoy being creative.	Myself	11/09/2017

Care and support plan

Needs, concerns or health problems	Goals	Stage goal	Actions		Outcomes	Person completing record
Mental health	Overall goal: no symptoms Smallest improvement: feel more alert in the day. Do my breathing exercises.		1) Take medication at night 2) Work with my therapist on my abuse history and not feeling afraid. 3) Think through a COPD attack and a panic attack. 4) Discuss medication	1) **Who:** Myself **Status:** Completed 2) **Who:** Myself **Status:** Completed 3) **Who:** Myself 4) **Who:** Care-coordinator	Partially achieved 29/11/2018	**Name:** Tom Smith **Role:** Care-coordinator **Contact:** 020 345 6789, tom.smith5@nhs.net **Organisation:** MH NHS Trust

			options and support Sadie to seek out friends 5) Set reminder of when to take medication; encourage Sadie to go out of the house regularly.	5) **Who:** Family **Date:** 11/09/2017 **Planned review date:** 11/02/2018		
Physical health	Overall goal: Less breathless because of COPD, able to exercise more. Smallest Improvement: do my breathing exercises daily rather than weekly and so feel less wheezy		1) Breathing exercises 2) Check with physiotherapist and ensure breathing exercises and physical exercises are lined up with psychology advice 3) Check with community pharmacist re drug interactions	1) **Who:** Myself 2) **Who:** Myself **Status:** Completed 3) **Who:** Care-coordinator **Date:** 11/09/2017 **Planned review date:** 11/02/2018	Partially achieved 29/11/2018	**Name:** Tom Smith **Role:** Care-coordinator **Contact:** 020 345 6789, tom.smith5@nhs.net **Organisation:** MH NHS Trust
			Daily breathing and physical exercise programme. 10 repeats of each exercise x2 daily	**Who:** Myself **Date:** 29/11/2017 **Planned review date:** 11/02/2018		**Name:** Tom Robbins **Role:** Physiotherapist **Contact:** 020 345 6789, t.robbins@nhs.net **Organisation:** NHS Trust

Job situation	Overall Goal: to return to school teaching next academic year. Smallest improvement: To practice lesson planning		1) Buy paper for lesson planning and plan three lessons by next month. 2) One friend to practice lesson with.	1) **Who:** Myself 2) **Who:** Friend **Date:** 11/09/2017 **Planned review date:** 11/02/2018	On-going	**Name:** Tom Smith **Role:** Care-coordinator **Contact:** 020 345 6789, tom.smith5@nhs.net **Organisation:** MH NHS Trust
Leisure activities	Overall goal: to go out twice a week, once on own and once with a friend Smallest improvement: to go shopping once with a friend and to stay out until the panic subsides.		1) Identify a day to go out 2) To go out for a planned two hours.	**Who:** 1) **Who:** Myself 2) **Who:** Friend **Date:** 11/09/2017 **Planned review date:** 11/02/2018	On-going	**Name:** Tom Smith **Role:** Care-coordinator **Contact:** 020 345 6789, tom.smith5@nhs.net **Organisation:** MH NHS Trust
Medication	Overall goal: to reduce or adjust my medication so I have fewer or no side effects, particularly heart palpitations, sweats, lethargy, breathlessness.		1) Speak with psychiatrist about side effects 2) Liaise with COPD physician and physio re side effects	1) **Who:** Myself **Status:** Completed 2) **Who:** Care-coordinator **Date:** 11/09/2017 **Planned review date:** 11/02/2018	Partially achieved 22/09/2017	**Name:** Tom Smith **Role:** Care-coordinator **Contact:** 020 345 6789, tom.smith5@nhs.net **Organisation:** MH NHS Trust

		Reduce lethargy caused by medication	To trial alternative medication over the next month	**Who:** Dr J Brown, Consultant Psych **When:** Starting next week **Date:** 22/09/2017 **Planned review date:** 22/10/2017		**Name:** Dr Jon Brown **Role:** Consultant Psychiatrist **Contact:** 020 345 6789, job.brown14@nhs.net **Organisation:** MH NHS Trust
			Review prescribed medications for interactions and side effects	**Who:** J Moss, Pharmacist **Date:** 28/09/2017 **Planned review date:** 28/12/2017		**Name:** Janet Moss **Role:** Pharmacist **Contact:** 020 345 6789, j.moss@nhs.net **Organisation:** Pharmacy

Planned review date/interval	Responsibility for review	Agreed with person	Date this plan was last updated	Updated by
Every 6 months	Dr J Brown, Consultant Psychiatrist	Yes	29/11/2017	**Name:** Tom Robbins **Role:** Physiotherapist **Contact:** 020 345 6789, t.robbins@nhs.net **Organisation:** NHS Trust

7.5. Example 5

Example 5 includes additional relevant information added by the person to their 'about me' section at a later date. The care and support plan includes goals initially agreed between the person and their social worker and later updated in a consultation with GP. Several actions were originally referrals to specialists and these are now completed, with associated goals now including additional actions after patient's consultation with an occupational therapist and multiple sclerosis consultant nurse specialist.

One of the initially agreed and fully achieved goals have been archived as illustrated in the care and support plan appendix section, as the care and support plan only shows currently relevant goals and actions.

Contingency plan section illustrates additional plans being added at different dates and by different professionals as they were agreed with the person.

About me	Supported to write this by	Date
My name is Jane, I am 46 years old and have secondary progressive multiple sclerosis. I was diagnosed with MS 14 years ago. I don't have relapses anymore – but do get worse when I am poorly or have an infection. My MS means I have a bad tremor in both my arms when I am trying to do something. I also find it difficult to move my legs – so need to hold on to something when walking inside the house. I need help getting into the bath and doing up buttons/ bras and putting my socks on. My mum does all the cooking and cleaning and has to help me with cutting up my food. She also has emphysema so finds it more difficult to look after me now, especially helping me in and out of the bath. I live in Hackney with my mother in a two-bedroom maisonette. I used to live on my own but moved back home five years ago. I was a hairdresser and loved going out and being sociable. I used to be a regular at the Hackney Empire. I stopped working five years ago because I couldn't cut hair anymore due to my tremor. I really miss working. I can't go out for a cup of tea because I shake all over the place and people look at me.	Myself; Stephen Robins, Social Worker, 020 345 6789, srob@msc.gov,	16/01/2017
I find going out difficult now and have to use a three wheeled walker. I get tired, but also very wobbly and have fallen over before. I go shopping once a week with my mum. Most of my friends have busy family lives so I don't see them much.	Myself	01/09/2017

Care and support plan

Needs, concerns or health problems	Goals	Stage goal	Actions		Outcomes	Person completing record
Upper limb tremor	To be able to use my hands more		Referral to OT	**Who:** Social worker **When:** 16/09/2017 **Suggested strategies: Status:** Completed **Date:** 16/09/2017 **Planned review date:** 20/02/2018	On-going	**Name:** Stephen Robins **Role:** Social Worker **Contact:** 020 345 6789, srob@msc.gov **Organisation:** Adult social care
		Be able to put on makeup	To trial strategies and adaptive equipment	**Who:** Occupational Therapist **When:** Within a month **Suggested strategies:** Use weighted cuffs Lean through elbows on table set up **Status:** Started **Date:** 28/09/2017		**Name:** Sandra Laing **Role:** Occupational Therapist **Contact:** 020 345 6789, s.laing@nhs.net **Organisation:** NHS Trust
Urinary frequency and urgency	To be able to manage my bladder better.		Referral to MS specialist nurse	**Who:** GP **When:** 10/10/2017 **Suggested strategies:** Provision of inco pads **Status:** Completed **Date:** 10/10/2017	On-going	**Name:** Dr Kate Atkins **Role:** GP **Contact:** 020 345 6789, k.atkins@nhs.net **Organisation:** Surgery
			Referral to	**Who:** MS Consultant Nurse Specialist		**Name:** Olivia Smith

			incontinence service	**Suggested strategies:** Medication review **Status:** Completed **Date:** 28/10/2017		**Role:** MS Consultant Nurse Specialist **Contact:** 020 345 6789, o.smith@nhs.net **Organisation:** NHS Trust
Mobility/ Falls	To be able to get around better		Referral to physiotherapy to review mobility	**Who:** GP **When:** 10/10/2017 **Status:** Completed **Date:** 10/10/2017	On-going	**Name:** Dr Kate Atkins **Role:** GP **Contact:** 020 345 6789, k.atkins@nhs.net **Organisation:** Surgery
			Referral to occupational therapy to review bath transfers	**Who:** GP **When:** 10/10/2017 **Status:** Completed **Date:** 10/10/2017		
Social interaction	To go out more		1) Refer to local MS support group 2) ? look into voluntary work opportunities	**Who:** Occupational Therapist/Myself **Status:** Started **Date:** 28/09/2017 **Planned review date:** 20/02/2018		**Name:** Sandra Laing **Role:** OT **Contact:** 0203456789, s.laing@nhs.net **Organisation:** NHS Trust

Appendix – archived items removed from the main care and support plan view

Needs, concerns or health problems	Goals	Actions		Outcomes	Person completing record
Carer / respite	To help my mum more.	1) Care needs assessment 2) To trial ready meals 3) Contingency plan in place for potential hospital admission (mother)	**Who:** Social Worker **Status:** Completed **Date:** 16/09/2017 **Planned review date:** 20/02/2018	Fully achieved 28/09/2017	**Name:** Stephen Robins **Role:** Social Worker **Contact:** 020 345 6789, srob@msc.gov **Organisation:** Adult social care

Additional supporting plans

Plan name	Person completing record	Planned review date/interval	Responsibility for review
MS nurse care plan	Olivia Smith, MS Nurse, 020 345 6789, o.smith@nhs.net	Every 6 months	Olivia Smith, MS Nurse

Planned review date/interval	Responsibility for review	Date this plan was last updated	Updated by
Every 6 months	**Name:** Dr Kate Atkins **Role:** GP **Contact:** 020 345 6789, k.atkins@nhs.net **Organisation:** Surgery	28.10.17	**Name:** Olivia Smith **Role:** MS Consultant Nurse Specialist **Contact:** 020 345 6789, o.smith@nhs.net **Organisation:** NHS Trust

Contingency plans

Plan name	Trigger factors	What should happen	Who should be contacted	Anticipatory medicines/ equipment	Agreed with person	Person completing record	Date this plan was last updated	Planned review date	Responsibility for review
Multiple Sclerosis	Disease relapse	Early treatment	GP (urgently)	Steroids, Prednisolone 40mg daily	Yes	**Name:** Dr Kate Atkins **Role:** GP **Contact:** 020 345 6789, k.atkins@nhs.net **Organisation:** Surgery	10/10/2017	Every 6 months	**Name:** Dr Kate Atkins **Role:** GP **Contact:** 020 345 6789, k.atkins@nhs.net **Organisation:** Surgery
UTI	Urinary tract infection	Urine sample to GP Review antibiotics Antibiotic provision	GP/ MS CNS	Nitrofurantoin 100mg 4 times daily	Yes	**Name:** Dr Kate Atkins **Role:** GP **Contact:** 020 345 6789, k.atkins@nhs.net **Organisation:** Surgery	10/10/2017	Every 6 months	**Name:** Dr Kate Atkins **Role:** GP **Contact:** 020 345 6789, k.atkins@nhs.net **Organisation:** Surgery
Hospital admission plan	Hospital admission	I am a carer of my mother. If I am admitted to hospital, please contact social worker as emergency point of contact.	Social worker		Yes	**Name:** Stephen Robins **Role:** Social Worker **Contact:** 020 345 6789, srob@msc.gov **Organisation:** Adult social care	16/09/2017	Every 6 months	**Name:** Dr Kate Atkins **Role:** GP **Contact:** 020 345 6789, k.atkins@nhs.net **Organisation:** Surgery

7.6. Example 6

Example 6 illustrates a plan for a person who is unable to make decisions about their support and includes additional legal information from their record. An initial care and support plan was agreed by their Community Learning Disability Team. The plan was later updated by Epilepsy Nurse with their action noted. The plan was further reviewed and updated by the Team, and includes an additional action as well as an update on the progress of previous actions, several of which are now marked as partially achieved.

Epilepsy contingency plan was also updated at a later point in time after initial action for the care-coordinator to liaise with epilepsy nurse.

About me	Supported to write this by	Date
My name is Andrew, but I like to be called Andy. I am 19 years old. I love going for long walks and watching music videos on YouTube. I have autism and learning disabilities. I find it difficult to cope with changes that I don't expect. I have limited communication skills. I get anxious easily and when I am anxious I will ask for things that I know make me feel safe. I don't always want these things, but I want you to help me to be less anxious. I can't always explain to you clearly what I want. I also struggle to understand some things you tell me, particularly if this involves things that are abstract, like time. When I am anxious or excited I may try to run from my support. When I run I am not aware of risks and I may run into the road, even if it is busy and a car is coming. I have epilepsy. I have complex partial seizures where I usually hold my arm over my head. I also have tonic-clonic seizures when I will fall to the floor and shake. I have buccal midazolam prescribed for it if the seizures don't stop. It is important that you have read my epilepsy support plan to know how to support me when I have a seizure.	Care-coordinator, Tom Smith, LD Nurse, tom.smith5@nhs.net	02/02/2017

Deprivation of Liberty Safeguards or	Andy is unable to make decisions about his support. Deprivation of Liberty Safeguards have been authorised to reflect

equivalent	his need for two to one support and that he may be prevented from leaving his home if it is felt unsafe.
Lasting power of attorney for personal welfare or court-appointed deputy (or equivalent)	His parents have power of attorney for his finances, health and welfare. This means they may consent on his behalf and should be involved in all decisions.
Legal safeguarding issues	None
Mental Health Act or equivalent status	Andy has recently been detained in a specialist learning disability hospital under Section 3 of the Mental Health Act. He no longer has any restrictions. He is entitled to Section 117 aftercare arrangements from the Local Authority.
Mental capacity assessment	Please see capacity assessments relating to: - Finances - Health - Support

Care and support plan

Needs, concerns or health problems	Goals	Actions		Outcomes	Person completing record
Managing anxiety	To provide Andy with strategies for expressing and coping with anxiety. To reduce things that make him anxious.	- Regularly rehearse breathing exercises - Promote communication of "I am anxious" - Ensure consistent response from support to anxiety - Clear structured weekly timetable	**Who:** Community Learning Disability Team **Status:** Started **Date:** 02/09/2017	On-going	**Name:** Tom Smith **Role:** Care-coordinator **Contact:** 020 345 6789, tom.smith5@nhs.net **Organisation:** NHS Trust
Communication	To increase Andy's communication skills.	- Ensure Picture Exchange Communication System is in place and used consistently. - Clear communication	**Who:** Community Learning Disability Team **Status:** Not started	On-going	**Name:** Tom Smith **Role:** Care-coordinator **Contact:** 020 345 6789,

		guidelines to be followed by all. - Develop communication passport to share communication needs with others.	**Date:** 02/09/2017		tom.smith5@nhs.net **Organisation:** NHS Trust
Keeping safe	To manage the risk of Andy running into the road when anxious or excited.	- Develop a strategy to be used consistently by the team, e.g. encouraging "walk with me". - Using energy proactively with running activities. - Social story about road safety to be read before each outing. - Clear crisis plan for managing behaviour when running occurs.	**Who:** Community Learning Disability Team **Status:** Started **Date:** 02/09/2017	Partially achieved	**Name:** Tom Smith **Role:** Care-coordinator **Contact:** 020 345 6789, tom.smith5@nhs.net **Organisation:** NHS Trust
Epilepsy management	To ensure support is able to provide safe and effective support during seizures.	- Liaise with epilepsy nurse	**Who:** Care-coordinator **Status:** Completed **Date:** 02/09/2017	Partially achieved	**Name:** Tom Smith **Role:** Care-coordinator **Contact:** 020 345 6789, tom.smith5@nhs.net **Organisation:** NHS Trust
		- Share Epilepsy care plan with Community Learning Disability Team	**Who:** Epilepsy Nurse **Status:** Completed **Date:** 23/09/2017		**Name:** John Adams **Role:** Epilepsy Nurse **Contact:** 020 345 6789, john.adams1@nhs.net **Organisation:** NHS
		- All team members to be familiar with epilepsy support plan. - Rescue medication to be	**Who:** Community Learning Disability Team **Status:** Started		**Name:** Tom Smith **Role:** Care-coordinator **Contact:** 020 345 6789,

		available at all times. - Consistent recording of seizures to be followed to support Neurology reviews.	**Date:** 03/10/2017		tom.smith5@nhs.net **Organisation:** NHS Trust

Planned review date/interval	Responsibility for review	Date this plan was last updated	Updated by
Monthly	Community Learning Disability Team, **Contact:** 020 345 6788, CLDT@nhs.net **Organisation:** NHS Trust	03/10/2017	**Name:** Tom Smith **Role:** Care-coordinator **Contact:** 020 345 6789, tom.smith5@nhs.net **Organisation:** NHS Trust

Additional supporting plans

Plan name	Planned review date/interval	Responsibility for review
Epilepsy	Monthly	Epilepsy Nurse
Communication	Monthly	Speech & Language Therapist
Anxiety	Monthly	Learning Disability Nurse
Keeping safe	Monthly	Team manager

Contingency plans

Plan name	Trigger factors	What should happen	Who should be contacted	Anticipatory medicines/ equipment	Person completing record	Date this plan was last updated	Planned review date	Responsibility for review
Mental health	Andy is running away from support on more than one occasion per week	- Review physical health needs - Review anxiety - Review incidents and look for patterns - Increase supervision and support	- Parents - Community Learning Disability Team	Proactive use of PRN Lorazepam may be considered to reduce anxiety,	**Name:** Tom Smith **Role:** Care-coordinator **Contact:** 020 345 6789, tom.smith5@nhs.net **Organisation:** NHS Trust	02/09/2017	Monthly	**Name:** Tom Smith **Role:** Care-coordinator **Contact:** 020 345 6789, tom.smith5@nhs.net **Organisation:** NHS Trust
Epilepsy plan	Increase in seizure activity	- Review physical health - Increase monitoring	- Parents - Community Learning Disability Team - Neurology - Possibly GP	Ensure Buccal Midazolam is carried at all times	**Name:** John Adams **Role:** Epilepsy Nurse **Contact:** 020 345 6789, john.adams1@nhs.net **Organisation:** NHS Trust	23/09/2017	Monthly	**Name:** John Adams **Role:** Epilepsy Nurse **Contact:** 020 345 6789, john.adams1@nhs.net **Organisation:** NHS Trust

8. Appendix C – Stakeholders

This appendix describes the stakeholders who participated in the workshop, online survey and the expert group review.

Workshop attendees (05 April 2017) by organisation

Organisation	Name
Patient Representative	Ann Heaton
North West London Collaboration of CCGs	Bill Sturman
Scottish Government	Blythe Robertson
The Coalition for Collaborative Care	Cally Ward
Think Local Act Personal Partnership	Caroline Speirs
Homerton University Hospital NHS Foundation Trust/ Royal College of Occupational Therapists	Catherine Atkinson
The Coalition for Collaborative Care / NHS England	Catherine Wilton
South London and Maudsley NHS Foundation Trust	Charles Comley
Royal College of Nursing	Claire Buchner
NHS England	Clive Prince
Royal College of Physicians	Darren Wooldridge
Patients Know Best	David Boerner
National Voices	Don Redding
OLM Group	Ed Hagerty
Resuscitation Council (UK)	Federico Moscogiuri
Registered Nursing Home Association	Frank Ursell
Chelsea and Westminster Hospital	Gary Hartnol
Royal Pharmaceutical Society	Heidi Wright
Professional Record Standards Body	Helene Feger
Health Informatician / Accessibility	Howard Leicester
South Somerset Symphony Vanguard	Ian Wyer
Cerner	James Parrott
Royal College of Physicians	Jan Hoogewerf
Hertfordshire County Council	Jennifer McAteer
South Somerset Symphony	Joanne Cummings
Manchester City Council	Joe Kelly
Healthy London Partnership	John Arnett

Imperial College Healthcare NHS Trust	John Kelly
Thames Valley Strategic Clinical Network	Julia Coles
Royal College of Physicians	Kajal Mortier
NHS Digital/Association of Directors of Adult Social Services	Keith Strahan
British Dietetic Association	Kiri Elliott
The Coalition for Collaborative Care	Kristi Adams
Arthritis Research UK	Laura Boothman
Northumbria Healthcare / Year of Care Partnerships	Lindsay Oliver
Oxfordshire Clinical Commissioning Group	Merlin Dunlop
NHS Digital	Munish Jokhani
Durham Darlington Easington Sedgefield Primary Care trust/ General Practitioner	Neill Jones
North West London Collaboration of CCGs/ General Practitioner/ Royal College of General Practitioners CCSP Network	Nilesh Bharakhada
Hertfordshire Partnership University NHS Foundation Trust	Paul Bradley
Surrey Heartlands STP	Robert Smith
Professional Record Standards Body	Sarah Jackson
Royal Free London NHS Foundation Trust / British Association of Audiovestibular Physicians	Sebastian Hendricks
Royal College of Physicians	Sheena Jagjiwan
London Borough of Tower Hamlets, Principal Social Worker	Stella Smith
Civica	Stephen Hawkins
College of Paramedics	Steve Hatton
EMIS Health Ltd	Steve Roberts
Royal College of Nursing/ District Nurse	Susan Rayment
Oxfordshire CCG/ General Practitioner	Thomas Nichols
Cerner	Tim James
Private Healthcare Information Network	Vaibhav Joshi
North West London Collaboration of CCGs	Xavier Yibowei
ESP IT Consultancy Ltd/ Royal College of Nursing	Zabeda Ali-Fogarty
NHS Digital	Zac Whitewood-Moores

Workshop attendees (05 April 2017) by sector/role

Role	Number
Allied Health Professional	4
Commissioner	2
Industry	6
Informatician	4
Mental Health	2
Nursing	3
Other	6
Patient / carer	4
Pharmacist	1
Policy	1
Primary Care	7
Private Health	1
Professional Body	1
PRSB	1
Secondary care	2
Social care	6
Voluntary	4
Total	**55**

Online survey respondents (by role)

Role	Number	%
Allied Health Professional	110	18%
Commissioner	7	1%
Community nurse	30	5%
General Hospital Nurse	8	1%
General Practitioner	27	4%
Informatician	22	4%
IT System Supplier	16	3%
Manager	120	19%
Mental Health Nurse	4	1%
Patient / Carer / Service user	57	9%
Pharmacist	11	2%
Psychiatrist	4	1%
Secondary Care Doctor	42	7%
Social care worker	17	3%
Voluntary / Third sector worker	32	5%
Other	116	19%
Total	**623**	

Expert Reference Group attendees (20 October 2017)

Organisation	Name
NHS Digital	Adnan Azfar
North West London Collaboration of CCGs/ Royal College of General Practitioners CCSP Network	Nilesh Bharakhada
Imperial College Healthcare NHS Trust	Gerry Bolger
Royal College of Physicians / Royal College of Nursing	Claire Buchner
Royal College of Nursing	Matt Butler
College of Paramedics	David Davis
NHS Digital	Michael Folan
Royal College of Physicians	Jan Hoogewerf
Royal College of Physicians / NHS Digital	Neill Jones (Chair)
NHS Digital	Munish Jokhani
Royal College of Physicians / Adult Social Care	Joe Kelly
Northumbria Healthcare / Year of Care Partnerships	Nick Lewis-Barned
Royal College of General Practitioners CCSP Network	David Paynton
Royal College of Physicians	Haroldas Petkus
Patients Know Best	Shriti Rai
NHS Digital	Keith Strahan
Patients Know Best	Shailesh Suri
Registered Nursing Home Association	Ian Turner
North West London CCGs	Xavier Yibowei