



**Professional
Record
Standards
Body**

**Better records
for better care**



DIGITAL CARE AND SUPPORT PLAN STANDARD IMPLEMENTATION GUIDANCE

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.

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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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Professional Record Standards Body

32-36 Loman Street,
London, SE1 0EH.

www.theprsb.org

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Document Management

Revision History

Version	Date	Summary of Changes
0.1	26.10.2017	First draft
0.2	29.10.2017	Updated by Jan Hoogewerf, Programme Manager
0.3	23.11.2017	Updated following feedback from the Project Board and the Assurance Committee
0.4	14.12.2017	Updated following feedback from advisers and the Project Board
0.5	15.01.2018	Updated following additional feedback
0.6	31.01.2018	Updated following feedback from advisers and the Project Board
0.7	07.02.2018	Edited for consistency
0.8	15.02.2018	Final draft
0.9	19.02.2018	Final draft for publication
1.0	20.03.2018	Final draft for publication

Planned Review Date and Route for User Feedback

The next maintenance review of this document is planned for March 2021, subject to agreement with NHS Digital as the commissioning body.

Please direct any comments or enquiries related to the project report and implementation of the standard to support@theprsb.org.

Reviewers

This document must be reviewed by the following people:

Reviewer name	Title / Responsibility
Bill Sturman	Director of Informatics, NWL Collaboration of CCGs (Chair)
Dr Neill Jones	Senior Clinical Advisor NHS Digital, GPsoc and GP2GP programs\GP Durham Darlington Easington Sedgefield Primary Care trust (Clinical lead)
Dr Nilesh Bharakhada	NWL Digital Care Plans Clinical Responsible Officer, RCGP National Champion for implementing Collaborative Care and Support Planning into practice
Ann Heaton	Patient representation
Jan Hoogewerf	Programme Manager, RCP
Martin Orton	Director of Delivery & Development, PRSB
Dr Munish Jokhani	Clinical Engagement Lead, NHS Digital
Xavier Yibowei	Digital Services Lead, NWL Collaboration of CCGs
Michael Davies	Local Digital Roadmap Lead, NHS NW London
Ian Turner	Managing Director, The Partnership in Care and Chair, Registered Nursing Home Association
Helen Donovan	RCN Professional Lead for Public Health
Naomi Hankinson	Royal College of Occupational Therapists
Keith Strahan	Principle Implementation and Change Manager – Social Care, NHS Digital and representative of the Association of Directors of Adult Social Services
Adnan Azfar	Senior Business & Implementation Manager, NHS Digital

Approved by

This document must be approved by the following people:

Name	Signature	Date
Project Board	Signed off	01.03.2018
PRSB Assurance Committee	Signed off	07.11.2017

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

Implementation guidance

Purpose

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

Background and definition

- 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 partner¹ 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 Voices²).
- 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”.³
- 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.
- 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.
- 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.
- 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.

¹ The professional or supporter you work with could be a doctor, nurse or social worker, another professional or someone from a support organisation.

² <https://www.nationalvoices.org.uk/>

³ <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#person-centred-care-and-support-planning>

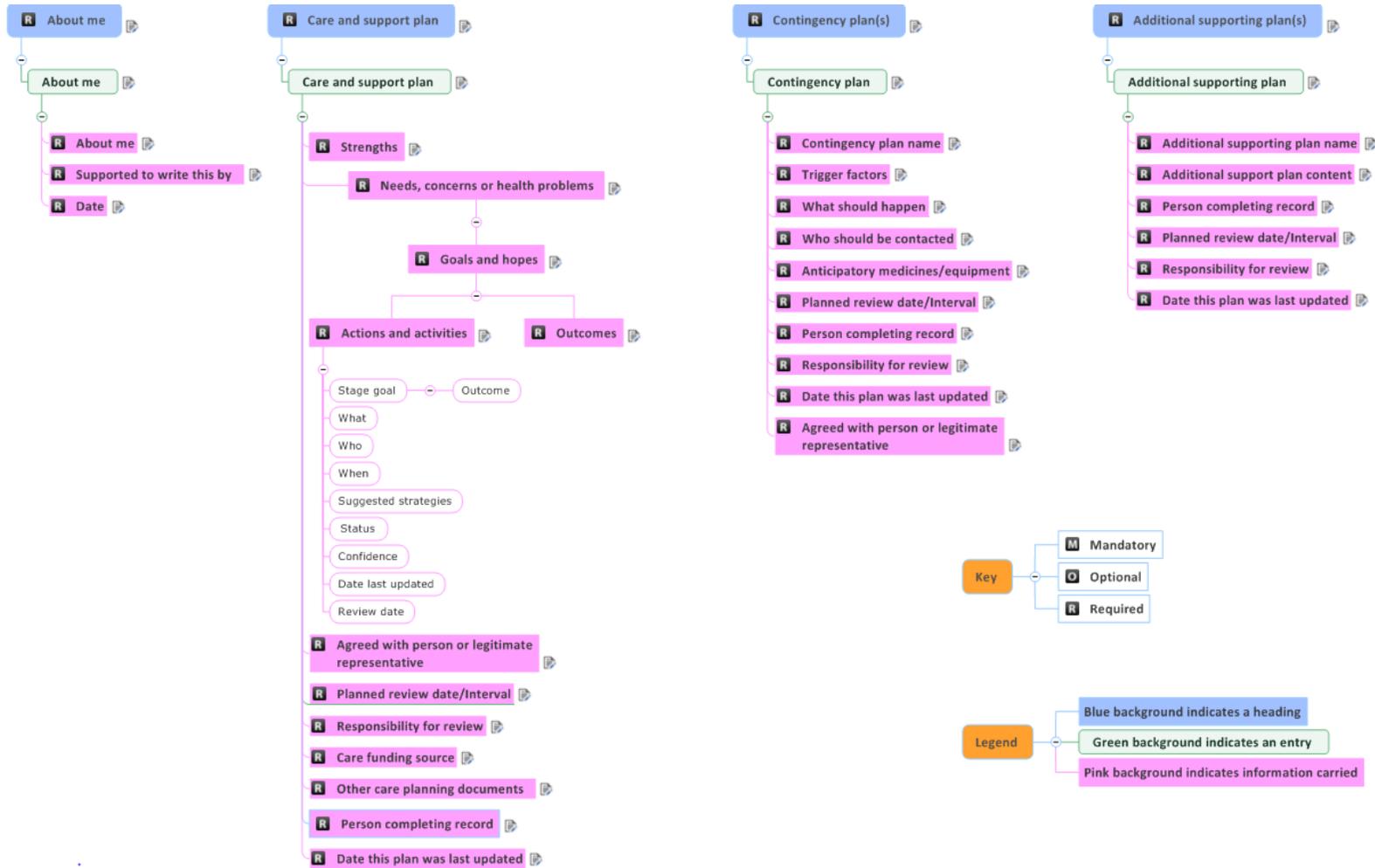
- Some people also have a plan which set out their wishes and preferences for care should they lack the capacity to articulate these wishes in an emergency situation. They are developed through a process that creates personalised recommendations for a person's clinical care in a future emergency in which 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 ReSPECT⁴ was developed by the Resuscitation Council (UK)⁵ and other organisations.

⁴ <http://www.respectprocess.org.uk/>

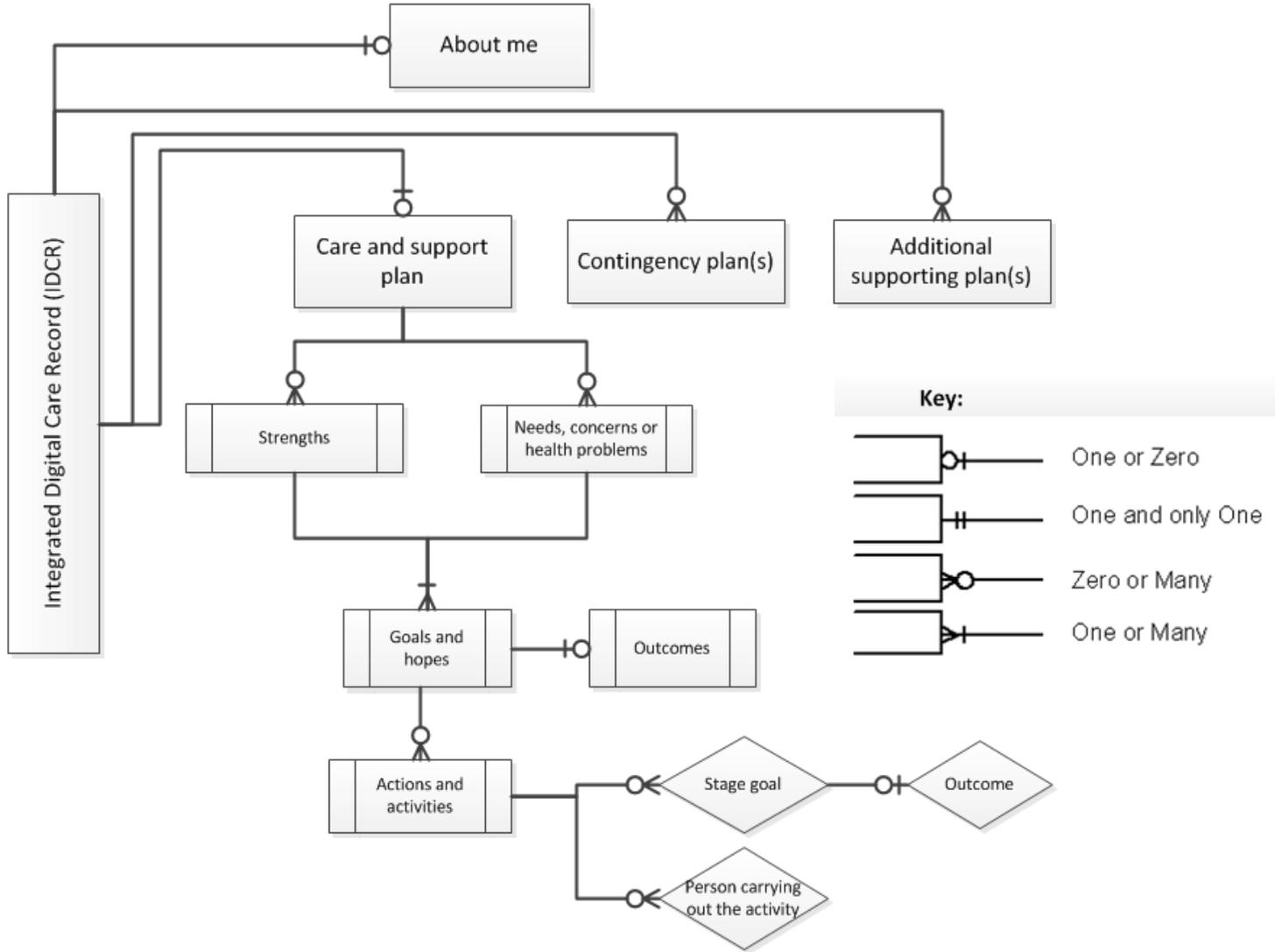
⁵ <https://www.resus.org.uk/>

Content

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



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

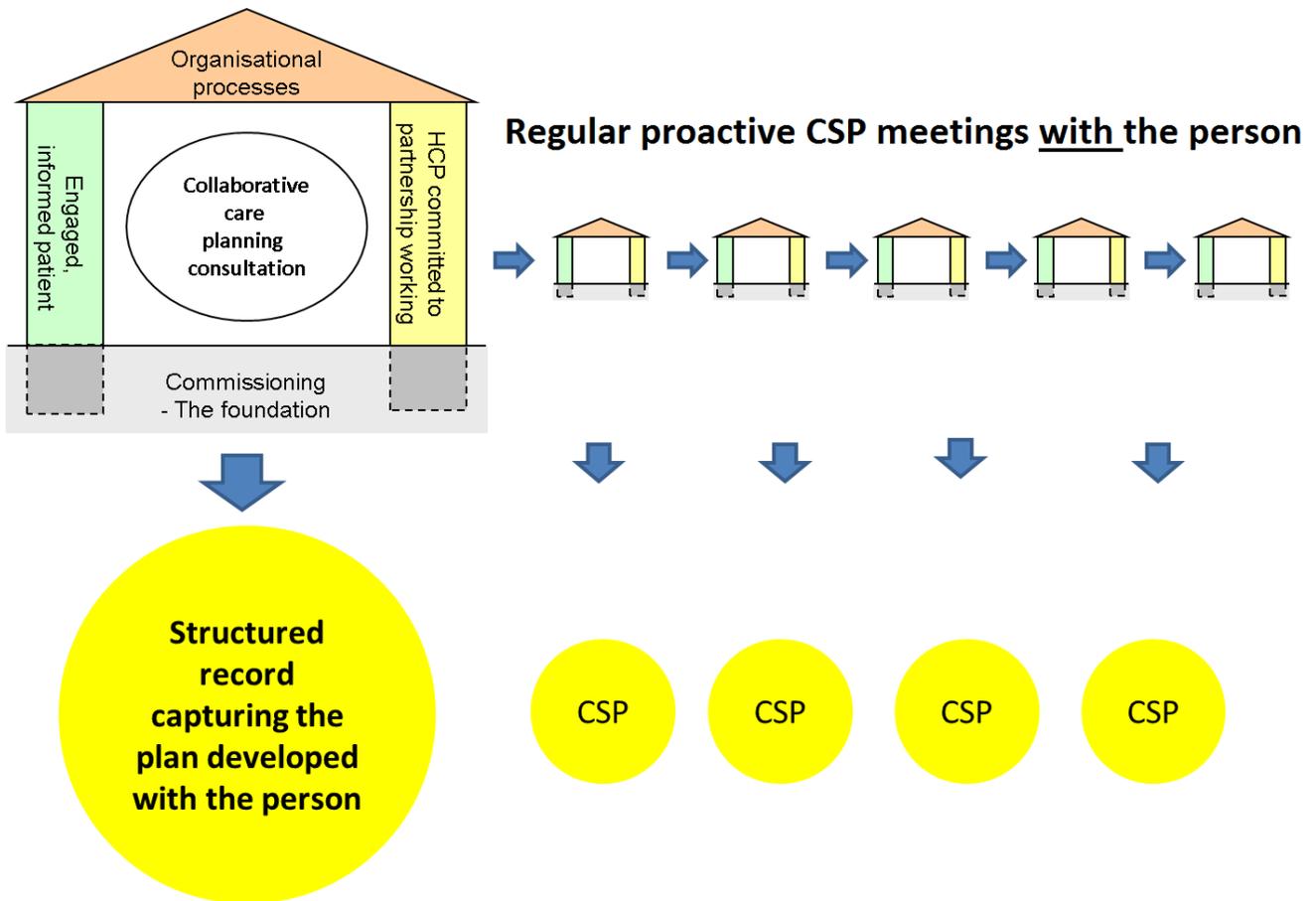


Scope of use

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

- The House of Care⁶ framework for long term conditions can be used to illustrate a care and support planning process:

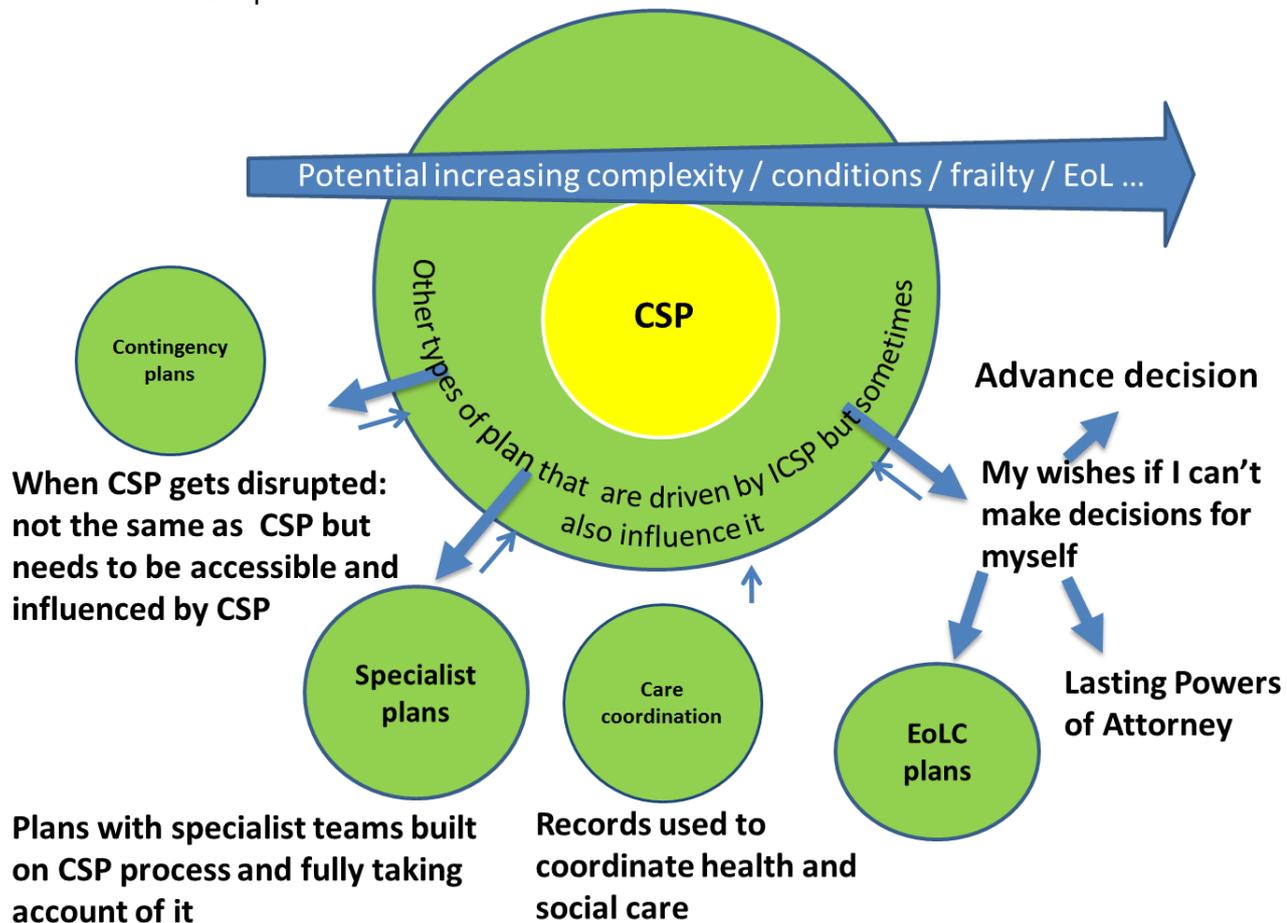


- Care and support planning is a process directed by the individual in which other people may be needed to help with developing and delivering. It is developed / adapted progressively over time and owned by the individual.
- The documentation of the care planning process is the care and support plan. It is owned by the individual and shared with others with consent.
- Supporting actions may be added by other professionals, if agreed with the person, to support them to achieve their goals.

⁶ <https://www.england.nhs.uk/ourwork/ltc-op-eolc/ltc-eolc/house-of-care/>
Digital care and support plan standard

Care planning context

- 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.
- The care and support plan should demonstrate how the person's aims and goals will be met.
- The figure⁷ below illustrates an example of the relationship between a care and support plan and other care plans.



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

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

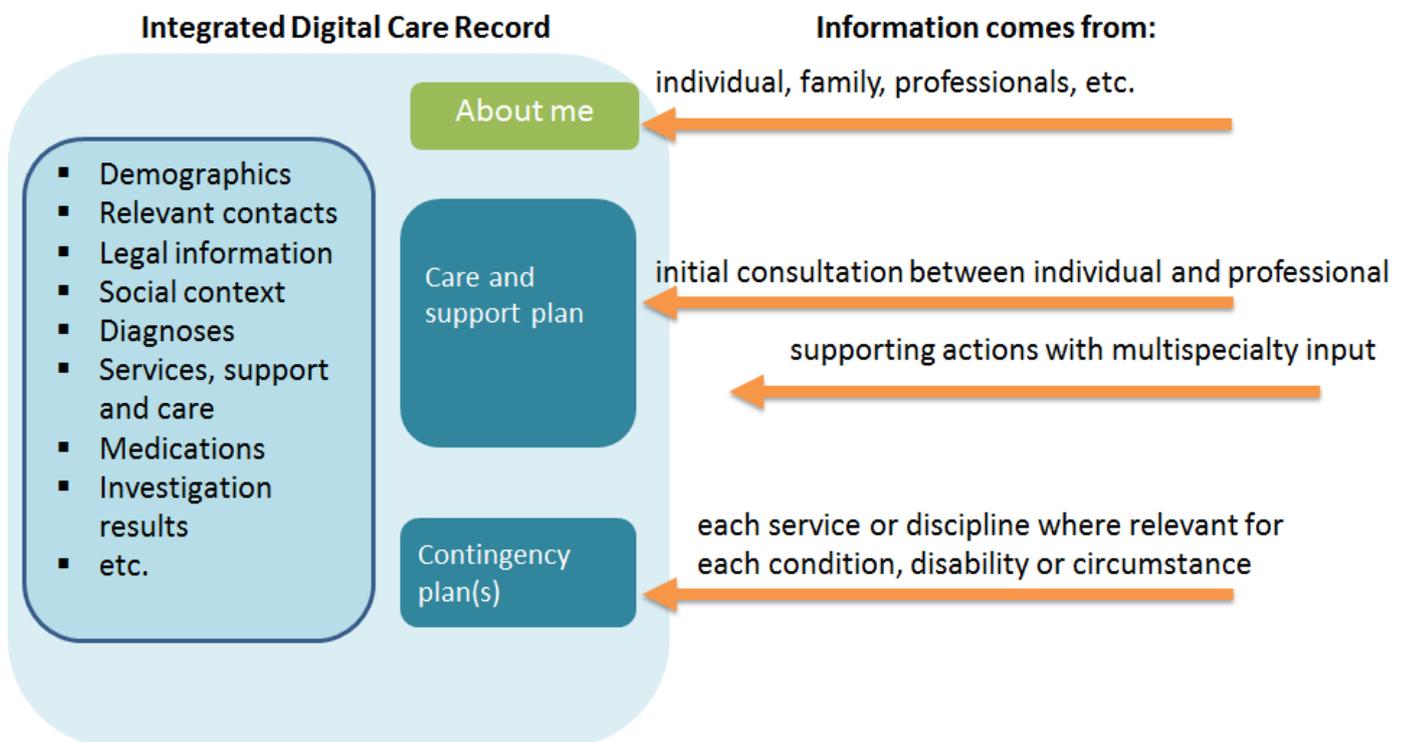
Plan and requested actions is a heading included in transfers of care such as discharge summaries and outpatient letters, to make clear who is expected to take responsibility for actions following transfer of care, e.g. the hospital, patient or GP. It may also include information about whether the patient 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)⁸ 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.

⁷ Thanks to Nick Lewis-Barned and the Year of Care programme.

⁸ *Crisis care summary standard*. PRSB. <https://theprsb.org/publications/crisis-care-standard>

- 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).
- 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.
- 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

- '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.
- '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.
- '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.
- It should be possible to store a history of applied changes and access previous versions of this information after any changes are made.
- '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 individual⁹. As an example, it could include:

⁹ For additional examples, see *Personalised care & support planning. Think Local Act Personal.*
www.thinklocalactpersonal.org.uk/personalised-care-and-support-planning-tool/
Digital care and support plan standard

Example 1	<ul style="list-style-type: none"> 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 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	<ul style="list-style-type: none"> 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

- 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

- 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.
- 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.
- It should be possible for a care and support plan to be recorded by an individual and/or a health or care professional.
- 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.
- It should be possible to add attachments or hyper-links in care and support plans to provide guidance, learning materials, explanatory notes, etc.
- 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).
- It should be possible to prioritise goals, indicating the importance of each goal to the person (e.g. a scale 1 to 10).
- 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).
- 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.
- Agreement of the plan with the person (or representative) should be recorded. If agreement cannot be obtained the reason for this should be documented.
- 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.
- 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.
- 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

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

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

Contingency plans

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

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

- 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	<ul style="list-style-type: none"> ○ 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	<ul style="list-style-type: none"> ○ Action Plan ○ Care and Personal Support Plan ○ Care Delivery Plan

	<ul style="list-style-type: none"> ○ 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	<ul style="list-style-type: none"> ○ Goals of care ○ Goals, aspirations or wishes ○ What I want to achieve ○ Desired outcome
Actions	<ul style="list-style-type: none"> ○ Activities ○ Proposed care and support
Outcomes	<ul style="list-style-type: none"> ○ Meeting goals set ○ My desired outcomes ○ Review ○ What that looks like
Contingency plan	<ul style="list-style-type: none"> ○ 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	<ul style="list-style-type: none"> ○ What might go wrong
What should happen	<ul style="list-style-type: none"> ○ Suggested actions
Anticipatory medicines/ equipment	<ul style="list-style-type: none"> ○ What I might need

Wider context

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



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