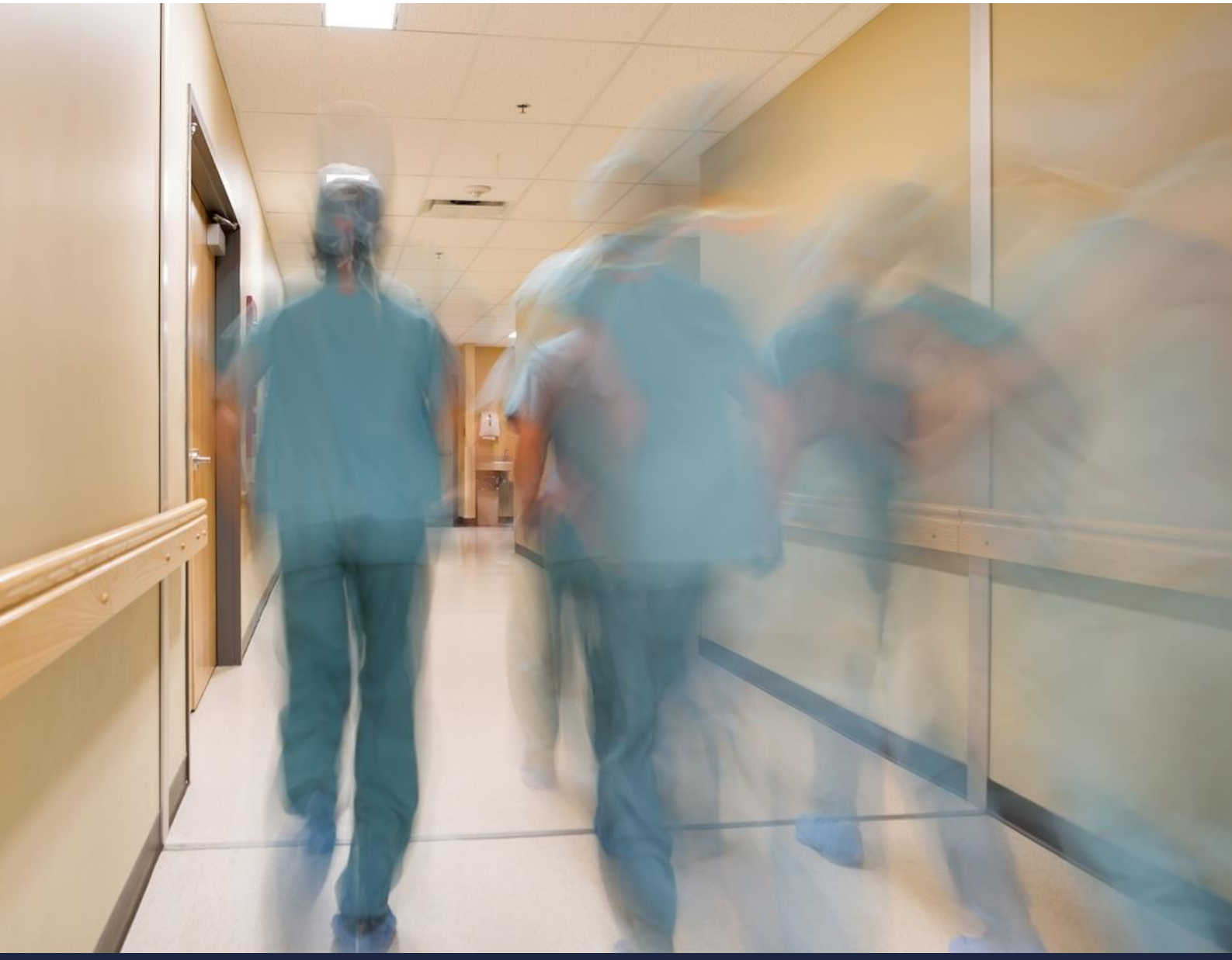
Professional Record Standards Body

Better records for better care



CRISIS CARE DOCUMENTATON PROJECT

JANUARY 2017

Acknowledgements

This project was funded by the Healthy London Partnership (HLP). The HLP is sponsored by the 32 clinical commissioning groups (CCGs) and NHS England (London Region) with the aim of taking London from position 7 to position 1 in the global healthy city rankings. As one of the 13 sponsored programmes, the Interoperability Programme is responsible for delivering the vision of paperless, real time sharing of health and care information under the control of the citizen, across the 32 CCGs and beyond, by 2020. In doing so, the programme aims to support strategic business transformation across a number of areas of health and care including urgent and emergency care (UEC), Cancer, Personalisation and Participation, Primary Care and Mental Health.

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.

Professional Record Standards Body
32-36 Loman Street,
London SE1 0EH

www.theprsb.org
support@theprsb.org

Community Interest Company No 8540834

Project	Crisis care documentation project		
Project Director	Matthew Whitty		
Owner	Darren Wooldridge	**Version**	2.2
Authors	Darren Wooldridge/ Jan Hoogewerf/Paul Rastall/Joseph Dent		
Version Date	26.01.2017	**Status**	Final

Document management

Revision history

Version	Date	Summary of Changes
01	15.03.2016	First draft created by Darren Wooldridge
02	21.03.2016	Updated by Jan Hoogewerf
03	06.04.2016	Updated following project board review
1.0	07.04.2016	Signed off by project board
1.1	25.04.2016	Updated ADRT and LPA headings for comments by David Pitcher
2.0	17.05.2016	Updated following comments from PRSB Advisory Board members
2.1	18.10.2016	Corrections of spelling and grammar
2.2	26.01.2017	New report cover added

Glossary of terms

Term / Abbreviation	What it stands for
ADRT	Advance Decision to Refuse Treatment
AoMRC	Academy of Medical Royal Colleges
CCG	Clinical Commissioning Group
CDGRS	Clinical Documentation and Generic Record Standards
CHI	Community Health Index
CMC	Coordinate my Care
CPR	Cardiopulmonary Resuscitation
DoLS	Deprivation of Liberty Safeguards
DM+D	NHS Dictionary of Medicines and Devices
DMS	Domain Message Specification

ECTP	Emergency Care Treatment Plan
ED	Emergency Departments
EHR	Electronic Health Record
EoLC	End of Life Care
ePACCS	Electronic Palliative Care Coordination System
GMC	General Medical Council
HCPC	Health and Care Professions Council
HIU	Health Informatics Unit
HLP	Healthy London Partnership
HSCIC	Health and Social Care Information Centre
IHE	Integrating the Healthcare Enterprise
IM	Intramuscular
IMCA	Independent Mental Capacity Advocate
ISB	Information Standards Board
IUC	Integrated Urgent Care, i.e. NHS 111 and GP out of hours
IV	Intravenous
LPA	Lasting Power of Attorney for Personal Welfare
OOH	Out of Hours
NG	Nasogastric (tube)
NPSA	National Patient Safety Agency
PEM	NHS 111 post event messages
PID	Project Initiation Document
PRSB	Professional Record Standards Body for Health and Social Care
RCEM	Royal College of Emergency Medicine
RCP	Royal College of Physicians
SPN	Special Patient Notes
ToC	Transfer of Care
UEC	Urgent and Emergency care

Reviewers

This document must be reviewed by the following people:

Reviewer name	**Title / Responsibility**
John Arnett	HLP Interoperability Programme
Munish Jokhani	NHS Digital, Clinical Engagement Lead
Dave Barnett	NHS Digital, Messaging Team

Lorraine Foley	PRSB, Chief Executive Officer
Matthew Whitty	PRSB, Programme Director
Caroline Stirling	Clinical Director, End of Life Care Clinical Network, NHS London
Alastair Crisp	Senior Programme Manager (NHS England London Region)
Mike Part	Head of Digital, NHS England London region
Bernadette Worman	Information and Communications Technology Project Manager, NHS England London Region
Philip Scott	PRSB, Technical Assurance
Annette Gilmore	PRSB Clinical and Patient Assurance
Phil Koczan	GP/CCG representative

Approved by

This document must be approved by the following people:

Name	Signature	Date	Version
Project Board	Signed off	07.04.2016	0.3
PRSB Advisory Board	Signed off	12.05.2016	1.1

Related documents

These documents will provide additional information.

Ref no	Title
[1]	Crisis care summary standard headings and content definitions (final draft)
[2]	Crisis care summary information model spread sheets (final draft)
[3]	Crisis care summary information model mind maps (final draft)
[4]	Transfer of care from ambulance to ED standard headings and content definitions (final draft)
[5]	Transfer of care from ambulance to ED information model spread sheets (final draft)
[6]	Transfer of care from ambulance to ED information model mind maps (final draft)
[7]	Professional Guidance on the Structure and Content of Ambulance Records https://www.rcplondon.ac.uk/projects/professional-guidance-structure-and-content-ambulance-records
[8]	Standards for the Clinical Structure and Content of Patient Records. http://www.rcplondon.ac.uk/resources/standards-clinical-structure-and-content-patient-records

[9]	Palliative care co-ordination: core content
[10]	Draft Emergency Care Data Set
[11]	SPN Shortlisting by NHS 111 Regional Clinical Leads Briefing 26/01/2015
[12]	Clinical Documentation and Generic Record Standards Lessons Learned Report
[13]	Professional Records Standards Body Service Specification 2014/15
[14]	PRSB work programme 2015 Lessons Learned Report
[15]	Crisis care documentation draft message specification (DMS)
[16]	PRSB assurance criteria

Contents

1. Purpose

In order for health and care information to be shared and re-used safely in an electronic environment a standardised structure is required. The standard needs to meet the needs of patients and the healthcare professionals involved in their care and reflect the ways in which they work. In urgent and emergency care (UEC), information about patient care plans and preferences can help to ensure that they receive appropriate care and avoid unnecessary admission to hospital, or treatment that they do not want. Information needs to be shared quickly throughout an emergency care pathway so that a patient doesn't need to repeat information and care services have the information they need to deliver safe and effective care. The purpose of the project was to define a standard structure and content of crisis care documentation in consultation with patients and healthcare professionals.

2. Introduction

The Healthy London Partnership (HLP) Interoperability Programme commissioned the Professional Record Standards Body (PRSB) to develop standard headings and content definitions, supported by information models for crisis care documentation. The project was carried out by the Royal College of Physicians (RCP) Health Informatics Unit (HIU) on behalf of the PRSB.

Within the context of this project the term 'crisis' is defined as an event which needs sudden intervention. As well as urgent or emergency physical health needs, an individual's crisis may be caused by a mental health problem. An individual's crisis may also result in a need for health or social care support for a dependant (e.g. a patient with dementia whose relative suddenly falls unwell and needs to be admitted to hospital may need social care).

From the patient's perspective, no distinction is made between urgent and emergency care needs – both are perceived as requiring attention on the same day as they arise. From a clinician's perspective, however, emergency needs are defined as being time critical, whereas urgent needs are not. However, the clinical urgency of a problem cannot be determined until it is clinically assessed (i.e. triaged). Crisis care is a term used to describe any activity undertaken to manage a crisis or prevent escalation and is provided by urgent and emergency care services (e.g. Integrated Urgent Care [IUC], ambulance and emergency departments [ED] as well as by primary, community and mental health services).

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

- **Crisis care summary:** information which needs to be shared to enable triage of patients in a crisis. This information will be used primarily to inform decisions about resource allocation in crisis.
- **End of life care plan:** to support the coordination of end of life care (EoLC) between primary care, acute care, community care, UEC, Electronic Palliative Care Coordination Systems (EPaCCS), such as Coordinate my Care (CMC), hospices, care homes, social care services and the patient and his or her carers.

This will be built upon data recorded for the purpose of planning care. It will provide the content required for planning and managing EoLC.

- **Crisis care encounter and transfer of care (ToC) information***: the record of the crisis care encounter which is passed to another service at transfer of care. This would currently include NHS 111 or ambulance dispatch to ambulance paramedics, NHS 111 to GP out of hours (OOH), GP OOH to GP, and ambulance paramedics to ED.
- Standard headings and content definitions (as set out in PRSB editorial principles).
- Supporting information models, comprising mind maps and spreadsheets: identifying the headings and their definitions, whether they are mandatory or optional and the content (values) that can be recorded under the headings.

The crisis care documentation standard is consistent with the 2013 Academy of Medical Royal Colleges/now the PRSB Clinical Documentation and Generic Record Standards (CDGRS), which include referral, outpatient letters, admission, handover and discharge summary and the 2014 professional guidance for ambulance records. The standard headings and content definitions are generic across all record standards, so that they can be used consistently across different use cases and care settings.

**Please note that the scope of the project changed to focus specifically on the transfer of care information from ambulance to ED departments only. This was because it became apparent at the first consultation workshop on 18 January 2016 that the content of the information flows between the different services involved in crisis care was too diverse for it to be feasible to develop standards for all transfers of care in the time available for this project. A separate PRSB report (Ambulance transfer of care to emergency departments documentation standards) describes the transfer of care headings.*

This report sets out the methods used in the project and the stakeholders with whom the project team engaged. It accompanies the information model mind maps and spreadsheets, which are separate documents.

3. Using the standard

A full electronic health record (EHR) should include all the headings in section 5, which will be displayed for data recording, reviewing and communicating.

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 patient. Furthermore any headings under which information is not recorded, should not be included in the crisis care summary.

A small number of the headings are identified as ‘mandatory’, meaning that they must be included in every crisis care summary. Others are identified as ‘required’, meaning that it is good practice to include them in communications, where information has been recorded for a specific patient and others are ‘optional’, meaning that it is a local decision whether or not to include them. Local agreements will need to be reached between participating organisations regarding which of the optional headings will be included in local communications.

The order or sequence in which the headings appear in EHR systems and communications can be agreed locally by system providers and end users.

4. Methodology

The following approach was taken to develop the standard headings and content definitions (with supporting information models):

Mapping of existing standards and documentation currently used
The project team identified a number of relevant data standards and documentation currently used in crisis care across the UK. This information was mapped to identify commonality and to inform an initial draft of standard headings and content definitions to be consulted on at the first consultation workshop. The data standards and documentation included:

- Academy of Medical Royal Colleges (AoMRC): Standards for the Structure and Content of Clinical Records, published in 2013 (now the PRSB standards)
- Headings used in the CMC (ePACCS) system
- Healthcare Improvement Scotland: Electronic Palliative Care Summary
- Health and Social Care Information Centre (HSCIC) and Royal College of Emergency Medicine (RCEM): Draft Emergency Care Data Set
- HSCIC: NHS 111 Domain Message Specification
- HSCIC: Out of Hours Domain Message Specification
- HSCIC: Palliative Care Co-ordination: Core Content Information Standard (ISB1580)
- HSCIC: Professional Guidance on the Structure and Content of Ambulance Records
- HSCIC: Summary Care Record inclusion/exclusion datasets
- Integrating the Healthcare Enterprise (IHE): Patient Care Plan Content Profile
- NHS National Services Scotland. National Information Systems Group: Key Information Summary
- Resuscitation Council: Emergency Care and Treatment Plan (ECTP)
- Special Patient Note (SPN) templates being used nationally by out of hours (OOH) providers, including an analysis by the NHS 111 Futures team about the different reasons for which SPNs are being created.

Additionally NHS 111 post event messages (PEM) were mapped to the AoMRC/PRSB record headings (see appendix A) to identify commonality and variances.

Consultation workshop
The initial draft standard headings and content definitions were discussed in a consultation workshop held on 18 January 2016, including patient representation, health/care professionals, academics and informaticians. Attendees are listed in Appendix B. The outcome of the workshop discussions informed a second draft of standard headings and content definitions and associated information models.

Online consultation survey
An online consultation survey was carried out between 05 February - 01 March 2016. A total of 373 people responded to the survey. Details of the survey were circulated to identified stakeholders including PRSB members, the PRSB vendor forum and the RCP HIU register. Contacted stakeholders are listed in Appendix B. The survey was used to obtain views on the content to be carried under the headings and informed updated versions of the standard headings and content definitions and associated information models (version 3). The findings from the survey can be found in Appendix C. The survey also raised a number of implementation issues which are discussed in section 4.

Expert user group meeting
Outstanding issues from the online consultation survey were discussed in an expert user group held on 14 March 2016, including patient representation, health/care professionals and vendors. Attendees are listed in Appendix B. The discussions informed an update of the standard headings and content definitions and associated information models (version 4), which was then circulated to the project board for their review and feedback. The expert user group also raised a number of implementation issues which are discussed in section 4.

Information models
Information models, in the form of mind maps and spreadsheets were developed by the project team. The team considered that the outputs would not be suitable for review by a general patient and health/care professional audience, e.g. due to the language used (e.g. model cardinalities, business values). Business values were identified through review of existing data sets. The consultation gained consensus on whether headings should be categorised as mandatory, required or optional. This is detailed in the information model spread sheets and mind maps. These are defined as:

- Mandatory headings: These headings should always be included in the message. Where there is no information then the message will contain appropriate coded text to identify this. Mandatory headings will be able to be tested technically to ensure that information is present.
- Optional headings mean that they may or may not contain information and hence cannot be technically tested. Guidance related to optional headings relates to good clinical recording practice. There are two types of optional heading:
    - Required, where information should be recorded (and communicated) if available.
    - Optional, where local decisions can be made about whether or not to record/communicate the information. For optional headings, where there is no information recorded under a heading, then the heading does not need to be included in the message.

5. Crisis care summary headings

This section presents the standard headings and content definitions that the consultation suggested should be included in a crisis care summary. It also describes which headings the consultation recommended should be mandatory (must be included in every communication), required (should be included if information is available under the heading) or optional (may be included, a local decision).

Please note that greyed out headings are only relevant for the specific use case of end of life care plans.

Person demographics		
Subheadings	**Description**	**Mandatory/required/optional**
Person name	The full name of the person.	M
Person preferred name	The name by which a person wishes to be addressed.	R
Person alias	Record details where a person is known to use assumed identities to access health/care services.	R
Date of birth	The date of birth of the person.	M
Sex	The person's phenotypic sex. Determines how the person will be treated clinically.	R
Gender	The person's stated gender (how the person wishes to portray themselves).	R
Ethnicity	The ethnicity of a person as specified by the person.	O
Religion	The religious affiliation as specified by the person.	O
NHS number	The unique identifier for a person within the NHS in England and Wales.	R
Other identifier	Country specific or local identifier, e.g., Community Health Index (CHI) in Scotland. Two data items: • type of identifier • identifier.	R
Person address	Person's usual place of residence.	M
Person telephone number	Telephone contact details of the person. To include, e.g., mobile, work and home number if available.	O
Relevant contacts	Include the most important contacts including: • Personal contacts e.g., next of kin, in case of emergency contact, lasting power of attorney,	R

	dependants, informal carers etc. • Health/care professional contacts e.g., social worker, hospital clinician, care coordinator, Independent Mental Capacity Advocate (IMCA) etc. Name, relationship, role (if formal role), contact details and availability, eg out of hours.	
Individual requirements		
Subheadings	**Description**	**Mandatory/required/optional**
Individual requirements	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.	R
GP practice		
Subheadings	**Description**	**Mandatory/required/optional**
GP name	Where the person or person's representative offers the name of a GP as their usual GP.	R
GP practice details	Name, address and telephone number of the person's registered GP practice.	M
GP practice identifier	The identifier of the registered GP practice.	R
Diagnoses		
Subheadings	**Description**	**Mandatory/required/optional**
Diagnosis	Confirmed active diagnosis. Include the stage of the disease where relevant.	R
Awareness of diagnosis	Description of the level of awareness the person and or their carer/family has regarding their diagnosis.	R
Relevant past medical, surgical and mental health history		

Subheadings	Description	Mandatory/required/optional
Relevant past medical, surgical and mental health history	The record of the person's significant medical, surgical and mental health history (will include dental and obstetric history). Including relevant previous diagnoses, problems and issues, procedures, investigations, specific anaesthesia issues, etc.	R
Problems and issues		
Subheadings	**Description**	**Mandatory/required/optional**
Problems and issues	Summary of current problems and issues. This would include significant symptoms or 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.	R
Clinical risks	Description of clinical risks identified e.g. problematic intubation, person with brittle diabetes, immuno-compromised/risk of infection etc.	R
Medications and medical devices		
Subheadings	**Description**	**Mandatory/required/optional**
Medication status	Whether or not a medication is currently used, previously used, authorised for future use.	M
Medication name	May be generic name or brand name (as appropriate).	M
Medication form	Eg capsule, drops, tablet, lotion etc.	R
Route	Medication administration description (oral, intramuscular [IM], intravenous [IV], etc.): may include method of administration, (e.g., by infusion, via nebuliser, via nasogastric [NG tube]) and/or site of use, (e.g., ‘to wound’, ‘to left eye’, etc.).	R

Dose	This is a record of the total amount of the active ingredient(s) to be given at each administration. It should include, e.g., units of measurement, number of tablets, volume/concentration of liquid, number of drops, etc.	R
Medication frequency	Frequency of taking or administration of the therapeutic agent or medication.	R
Additional instructions	Allows for: • requirements for adherence support, e.g., compliance aids, prompts and packaging requirements • additional information about specific medicines, e.g., where specific brand required • person requirements, e.g., unable to swallow tablets.	R
Reason for medication	Reason for medication being prescribed, where known.	R
Medication recommendations	Suggestions about duration and/or review, ongoing monitoring requirements, advice on starting, discontinuing or changing medication.	R
Medical devices	Any therapeutic medical device of relevance that does not have representation in the NHS dictionary of medicines and medical devices (dm+d).	R
Allergies and adverse reactions		
Subheadings	**Description**	**Mandatory/required/optional**
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.	M

Description of the reaction	A description of the manifestation of the allergic or adverse reaction experienced by the person. For example, skin rash.	R
Safety alerts		
Subheadings	**Description**	**Mandatory/required/optional**
Risks to self	Risks the person poses to themselves, e.g., suicide, overdose, self-harm, self-neglect.	R
Risks to others	Risks to care professional or others.	R
Risk from others	Details of where an adult or child is at risk from an identified person e.g. family member etc.	R
Legal information		
Subheadings	**Description**	**Mandatory/required/optional**
Consent for information sharing	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 or decision related to a minor.	R
Parental responsibility	For children this is a record of person(s) with parental responsibility.	R
Deprivation of Liberty Safeguards or equivalent	Record of Deprivation of Liberty Safeguards (DoLS) or equivalent, including the reasons for this.	R
Mental Health Act or equivalent status	Record where a person diagnosed with a mental disorder is formally detained under the Mental Health Act or equivalent, including the section number.	R
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	R

	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.	
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.	R
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.	R
Safeguarding issues	Any legal matters relating to safeguarding of a vulnerable child or adult, e.g., child protection plan, protection of vulnerable adult	R
Consent for creation of end of life care plan	Separate explicit consent is required for creation of an end of life care record. This records	R

	how this consent has been granted in order to differentiate between person's explicit consent, best interest decision, Lasting Power of Attorney decision and withdrawal of consent.	
Social context		
Subheadings	**Description**	**Mandatory/required/optional**
Household composition	E.g., lives alone, lives with family, lives with partner, etc. This may be free text.	R
Access	Special access requirements e.g. key safe, coded lock, which door to use, stretcher access, etc.	R
Dependants	Provide details of any responsibility the person has for dependants. In the case of minors provide additional details e.g., date of birth etc.	R
Services and care	The description of services and care providing support for person's health and social well-being.	R
Person and carer concerns, expectations and wishes		
Subheadings	**Description**	**Mandatory/required/optional**
Person and carer concerns, expectations and wishes	Description of the concerns, wishes or goals of the person as expressed by the person, their representative or carer. Where the person lacks capacity this may include their representatives concerns, expectations or wishes.	R
Preferred place of care	The preferences that a person has identified as their preferred place to receive care.	R
Preferred place of death	The preferences that a person has identified as their preferred place to die.	R
Advance statement	Written requests and preferences made by a person	R

	with capacity conveying their wishes, beliefs and values for their future care should they lose capacity. Include the location of the document if known.	
Crisis care plan		
Subheadings	**Description**	**Mandatory/required/optional**
Care funding details	A record of the funding source and any conditions or limitations associated.	R
Priorities of care	The priorities agreed between the person and their health/care team, where the person has capacity: • to get better; please consider all treatment to prolong life. • to achieve a balance between getting better and ensuring good quality of life; please consider selected treatments. • comfort; please consider all treatments aimed at symptom control.	R
Estimated prognosis	Where a person is terminally ill this is a clinical judgment indicating the anticipated period of time until death. E.g., last days, weeks, months or year of life. Also include the date the prognosis was made.	R
Awareness of prognosis	Description of the level of awareness the person and or their carer/family has regarding their estimated prognosis.	R
Anticipatory actions	Please provide guidance on specific interventions or actions that may be required or should be avoided in specific situations.	R
Anticipatory medicines/equipment	Medicines or equipment available in the event of a crisis and their location.	R

Agreed with person or legitimate representative	Indicates whether the crisis care plan was discussed and agreed with the person or legitimate representative. If agreement cannot be obtained the reason for this should be documented.	R
Cardio-pulmonary resuscitation (CPR) decision	Whether a decision has been made, the decision, who made the decision, the date of decision, date for review and location of documentation. Where the person or their family member/carer have not been informed of the clinical decision please state the reason why.	R
Planned review date	Date the plan is due for review.	R
End of life		
Subheadings	**Description**	**Mandatory/required/optional**
Certification of death	If person is in their last weeks of life, is there a doctor who has seen the person recently who could potentially sign a death certificate? Provide contact details.	R
Actions taken in anticipation of death	Plan that has been agreed to facilitate certification of death and/or funeral arrangements e.g. anticipatory discussions with coroner to arrange funeral within 24 hours etc.	R
Actual place of death	The location where the person actually died as recorded on the death certificate. If the person died somewhere other than their preferred place, record the reasons why this happened.	R
Cause of death	The cause of death as recorded on the death certificate.	R
Date of death	The date on which a person died or is officially deemed to have died, as recorded on the	R

	death certificate.	
Person completing record		
Subheadings	**Description**	**Mandatory/required/optional**
Name	The name of the person completing the record, preferably in a structured format.	M
Professional identifier	Professional identifier for the person completing the record e.g., General Medical Council (GMC) number, Health and Care Professions Council (HCPC) number etc or the personal identifier used by the local organisation.	R
Organisation	The organisation the person completing the record works for.	M
Role	The role the person is playing within the organisation at the time record was updated.	M
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.	O
Date and time completed	The date and time the record was updated.	M

6. Implementation principles

This section sets out issues identified from the workshop, online survey and expert user group which relate to implementation of the headings. They are noted in this section so that they can be used to inform implementation of the crisis care summary. They are not intended to be comprehensive, but just those issues identified at this stage. It is expected that further guidance will be produced from the experience of initial implementations.

Please also note the risk mitigations included in the clinical safety case for the crisis care summary (a separate document) as these should also be addressed during implementation.

General Points

- It is not anticipated that all headings will need to be used in all circumstances, only where they are relevant to a specific patient, ie headings should not be included in the message where there is no data recorded/available.
- Data quality and accuracy of coded data entry needs to be monitored and implementers will need to ensure sufficient training and monitoring of record keeping.
- The extent to which information can be taken into the hospital system in structured/coded format will depend on the capabilities of the hospital systems. Local decisions need to be made about what information is ingested into hospital systems in a structured coded format and what information is attached as a document.
- Local implementation plans need to be developed for the crisis care summary, including 'trading agreements' and associated information governance agreements between the organisations involved. These trading agreements should include:
    - Which fields can be automatically populated by drawing information from other records, such as the Summary Care Record, Integrated Digital Care Records, ePACCS, GP records etc. This will depend on the systems available locally, frequency of updates, etc.
    - The way that the content is laid out, including sequence or ordering of the headings, and which headings should be most prominently displayed.
    - Which of the headings should be mandatory/optional. This may be based on local requirements or system capabilities.
    - Which health/care professionals will have access to the crisis care summary and in what circumstances, including any restrictions applied to specific sections of the crisis care summary.
    - Mechanisms to validate the information in the crisis care summary during implementation.
    - Mechanisms to review the content of the crisis care summaries on a regular basis to ensure the information is up to date and valid.

Person demographics

- NHS number (or equivalent, e.g. CHI number in Scotland) is mandatory, but with the option to record not known or not available. Existing national guidance should be followed, including how to handle patients without an NHS number, eg overseas visitors, services personnel, prisoners.
- Spine compliant systems are needed to obtain traced NHS numbers. Where an organisation does not have a system linked to the Personal Demographics Service, other demographics fields will need to be used, with local person identity matching software.
- Hospital numbers are not unique so either avoid including them or reference the organisation where the number was generated.
- It is not anticipated that the 'sex' heading will be recorded on every crisis care summary – only in situations where it is pertinent to do so, e.g. transgender people.

- System design should allow the display of separate sections for health/care contacts and personal contacts (e.g. family, friends, relatives etc) under the ‘relevant contacts’ heading.

GP practice

- ‘GP practice identifier’ does not need to be a displayed field. It is intended to be used to provide the GP practice details via lookup from national registers.
- Many people will not offer a named GP. Only the ‘GP practice details’ heading would need to be completed in these situations.

Diagnoses

- For a crisis care summary it is important that only relevant active or current diagnoses are recorded, rather than all diagnoses, problems and issues that a patient may have. This should be determined by the clinician and patient.

Individual requirements

- Some of the information under this heading could be populated from the patient demographic service (e.g. person’s language etc), where it is recorded.

Safety alerts

- The safety alerts heading could potentially contain sensitive information. Therefore sufficient role based access controls should be in place to ensure this information is only shared with those care professionals where there is a need to do so.
- There may be situations where it not advisable to share information in this section with the person to whom it relates. Appropriate policies and technical solutions need to be in place for these situations.
- All information needs to be reviewed on a regular basis, but it is particularly important for this type of information, given its sensitive nature. There must be mechanisms in place to validate the information in this section and for it to be reviewed regularly.

Medications and medical devices

- System design must allow separate sections for display of current medications, previous medications and those authorised for future use, so that the status of each medication item is clear.
- Each attribute of the medication item (e.g. name, route, dose, frequency etc) should be presented in a clear and logical format (e.g. in tabular form). See National Patient Safety Agency (NPSA) guidance

(http://www.nrls.npsa.nhs.uk/resources/collections/design-for-patient-safety/?entryid45=66713).

- System design should allow for certain medications of particular importance (e.g. anticoagulants, steroids etc) to be prominently displayed so that they are not overlooked.

Allergies

- Separating out type of allergy/ adverse reaction/intolerance could require guidance/education.
- System design should allow for serious allergic reactions to be prominently displayed so that they are not overlooked.

Legal information

- The legislation relating to mental capacity in England is set out in the Mental Capacity Act 2005. The legislation in Scotland is set out in the Adults with Incapacity (Scotland) Act 2000 and in Northern Ireland, the Northern Ireland Mental Capacity Bill, was passed by the Northern Ireland Assembly on 15 March 2016, but has not yet come into force.
- Systems should allow copies of legal documentation to be attached to the record where it would be necessary to see the original documents (e.g. 'advance decision to refuse treatment', 'lasting power of attorney for personal welfare').
- A clinician should satisfy themselves that the ADRT is valid and that the circumstances that they are dealing with are those envisaged when the person made the ADRT. A valid and applicable ADRT is legally binding. The record should include the location of the legal document. A clinician should satisfy themselves that the ADRT is valid and that the circumstances that they are dealing with are those envisaged when the person made the ADRT. A valid and applicable ADRT is legally binding.
- Lasting power of attorney (LPA) should include details of one or more people who have been given power 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.
- To improve the accuracy of the 'organ and tissue donation' heading systems should link directly to the organ donation register where possible.

End of life

- The end of life care headings may only be relevant in specific circumstances. We have not been able to fully consider this use case in the time available. Further work will be needed to determine how it is implemented.

Person completing record

- 'Professional identifier' would not need to be a displayed field. It would be used to provide the professional's details.
- Multiple authors may contribute to the crisis care summary. The system must allow the provenance of the information to be at the data item level (linked to the author and the date of the entry).

For any implementation support related to the clinical content of the products outlined in this report, please email: support@theprsb.org.

Appendix A – NHS111 PEM mapping to equivalent record standard headings

NHS111 post event message heading	Equivalent record standard headings *(headings in capitals are navigational headings/headings in lower case are subheadings)*	Provenance of headings	Comments
Name	**PERSON DEMOGRAPHICS:** Person name	Crisis care summary 2015	
Born	**PERSON DEMOGRAPHICS:** Date of Birth	Crisis care summary 2015	
Gender	**PERSON DEMOGRAPHICS:** Gender	Crisis care summary 2015	
Unverified NHS No	**PERSON DEMOGRAPHICS:** NHS number	Crisis care summary 2015	Not exact match
Local Patient ID	**PERSON DEMOGRAPHICS:** Other identifier	Crisis care summary 2015	
Home Address	**PERSON DEMOGRAPHICS:** Person address	Crisis care summary 2015	
Home Phone	**PERSON DEMOGRAPHICS:** Person telephone number	Crisis care summary 2015	
GP Practice	**GP PRACTICE**	Crisis care summary 2015	

Patient's reported Condition	**PRESENTING COMPLAINTS OR ISSUES**	Ambulance transfer of care to A&E 2015	
Pathways Disposition	**DISPOSITION DETAILS**	Ambulance guidance 2014	Not a clinical decision - system generated advice
Consultation Summary	**CLINICAL SUMMARY**	Ambulance transfer of care to A&E 2015	
Advice Given	**INFORMATION AND ADVICE GIVEN**	Ambulance guidance 2014	
Document Created	**PERSON COMPLETING RECORD:** Date and time completed	Ambulance transfer of care to A&E 2015	
Document Owner	**PERSON COMPLETING RECORD:** Organisation	Ambulance transfer of care to A&E 2015	
Authored by	**PERSON COMPLETING RECORD:** Name	Ambulance transfer of care to A&E 2015	
Consent Status	**LEGAL INFORMATION:** Consent for information sharing	Crisis care summary 2015	
Encounter Type	**INCIDENT DETAILS:** Source of call	Ambulance guidance 2014	Not exact match
Encounter Time	**INCIDENT DETAILS:** Time call received	Ambulance transfer of care to A&E 2015	Not exact match
Case Reference	[redacted]		No mapping
Case ID			No mapping
Encounter Disposition	**DISPOSITION DETAILS**	Ambulance guidance 2014	
Care Setting Location	**INCIDENT DETAILS:** Incident location	Ambulance transfer of care to A&E 2015	
Care Setting Address	**INCIDENT DETAILS:** Incident location	Ambulance transfer of care to A&E 2015	
Care Setting Type	**INCIDENT DETAILS:** Incident location	Ambulance transfer of care to A&E 2015	
Responsible Party	**HEALTH AND CARE PROFESSIONAL DETAILS:** Responsible health or care professional	Ambulance transfer of care to A&E 2015	

Document ID	[redacted]		No mapping
Primary Recipient	**DISTRIBUTION LIST**	Ambulance guidance 2014	
Copy Recipient	**DISTRIBUTION LIST**	Ambulance guidance 2014	

Appendix B - Stakeholders

1. Individuals who attended the consultation workshop (18 January 2016)

Name	Organisation
Howard Leicester	Accessible Info
Keith Strahan	Association of Directors of Adult Social Services
Ian Turner	Care Provider Alliance
Sarah Montgomery	College of Occupational Therapists
Andy Jones	College of Paramedics
Andrew McFarlane	College of Paramedics
David Beck	Diabetes UK
Lis Warren	Diabetes UK
Charity Tshuma	East London Foundation Trust
Vena Jones-Pryce	East London Foundation Trust
David Barnett	Health and Social Care Information Centre
Munish Jokhani	Health and Social Care Information Centre
Afia Ansah	Healthy London Partnership
Bernadette Worman	Healthy London Partnership
Matthew Stevens	Healthy London Partnership
John Arnett	Healthy London Partnership
Tom Henderson	Healthy London Partnership
Rosa McNamara	Imperial College NHS Trust
Debbie Thomas	London Ambulance Service
Patrick O'Shea	Mencap
Harriet Harvey	NHS 111
Kate Griffiths	NHS 111
Miles Boyden	NHS 111
Helen O'Shaughnessy	NHS 111
Ossie Rawsthorne	NHS 111
Mark Bamlett	NHS England
Sonia Patel	NHS London
James Marple	NHS Lothian
Lea Agambar	North East London NHS Trust
Joseph Dent	North West Ambulance Service
Susan Rayment	Northamptonshire Healthcare NHS Foundation Trust
Paul Barratt	Partnership of East London Cooperatives
Annette Gilmore	Professional Record Standards Body
Lorraine Foley	Professional Record Standards Body
Neil Betteridge	Professional Record Standards Body
Philip Scott	Professional Record Standards Body
Anne Nevinson	RCP Patient and Carer Network
Deidre McLellan	RCP Patient and Carer Network
Jacky Macleod-Bridge	RCP Patient and Carer Network
Kim Fligelstone	RCP Patient and Carer Network
Ron Newall	RCP Patient and Carer Network
Sharon Ann North	RCP Patient and Carer Network
David Pitcher	Resuscitation Council

Name	Organisation
Darren Wooldridge	Royal College of Physicians
Jan Hoogewerf	Royal College of Physicians
Nicola Quinn	Royal College of Physicians
Paul Rastall	Royal College of Physicians
Julia Riley	Royal Marsden NHS Trust
Robin Lawrenson	Scottish Ambulance Service
Frances Gillen	South West Ambulance Service
Phil Koczan	UCL Partners
Caroline Stirling	University College London Hospital Palliative Care Service
Giles Armstrong	Whittington Hospital

2. **Stakeholders who were invited to participate in the online consultation survey (05 February -01 March 2016)**

- Accessible Info
- Age UK
- Allied Health Professions Federation
- Alzheimer's Society
- Association of Air Ambulances
- Association of Ambulance Chief Executives
- Association of Directors of Adult Social Services
- Asthma UK
- British Association For Immediate Care
- British Cardiovascular Society
- British Heart Foundation
- British Red Cross
- Care Provider Alliance
- Care UK
- Carers UK
- Chief Clinical Information Officers leaders network
- Clinical commissioning group lay members
- College of Paramedics
- Coordinate My Care
- Diabetes UK
- Epilepsy Society
- Genetic Alliance
- Health and Social Care Information Centre
- Health Chief Information Officers network
- Health Watch
- Healthy London Partnership
- HSCIC digital leaders community
- Independent Ambulance Association
- Mencap
- Mind
- Mumsnet
- National Care Alliance
- National Council Palliative Care
- NHS 111
- NHS 24
- NHS England
- Nursing Home Association
- PRSB members
- PRSB vendor forum
- RCP HIU register (individuals who have expressed an interest in the work of the HIU)
- RCP Patient and Carer Network
- Registered Nursing Home Association
- Resuscitation Council
- Royal College of Emergency Medicine
- Royal College of General Practitioners
- Royal College of Midwives
- Royal College of Nursing
- Royal College of Paediatrics and Child Health
- Royal College of Psychiatrists
- Royal Pharmaceutical Society
- TechUK

- UCL Partners
- UK Ambulance Services
- Young Minds

3. Individuals who attended the expert user group meeting (14 March 2016)

Name	Organisation
Joseph Dent	College of Paramedics
Andy Jones	College of Paramedics
Diana Howard	Coordinate My Care
David Barnet	Health and Social Care Information Centre
Munish Jokhani	Health and Social Care Information Centre
Afia Ansah	Healthy London Partnership
Matthew Stephens	Healthy London Partnership
James Marple	NHS Lothian
Ossie Rawsthorne	NHS111
Neil Betteridge	Professional Record Standards Body
Annette Gilmore	Professional Record Standards Body
Ian Turner	Registered Nursing Home Association
David Pitcher	Resuscitation Council
Tom Hughes	Royal College of Emergency Medicine
James Bird	Royal College of Nursing
Jan Hoogewerf	Royal College of Physicians
Paul Rastall	Royal College of Physicians
Darren Wooldridge	Royal College of Physicians
Hashim Reza	Royal College of Psychiatrists
Francis Gillen	South West Ambulance Service
David Partlow	South West Ambulance Service

Appendix C – Survey analysis

Total responses

There were a total of 373 responses, with the majority being doctors (100) and general practitioners (49). The breakdown was as follows:

Role	Number
Patient	31
Carer	11
General Practitioner	47
Out of hours General Practitioner	2
Palliative care doctor	7
ED doctor	16
Psychiatrist	17
Paediatrician	7
Any other doctor	53
Palliative care nurse	8
District nurse/health visitor	9
Mental health nurse	5
Hospital nurse	18
Any other nurse	12
Midwife	23
Paramedic	34
Pharmacist	3
Any other allied health professional	11
Social care	8
NHS111/ NHS24	5
Health/care manager	19
Health informatician	5
Vendor/developer	4
Other	18
Total	**373**

Identified issues

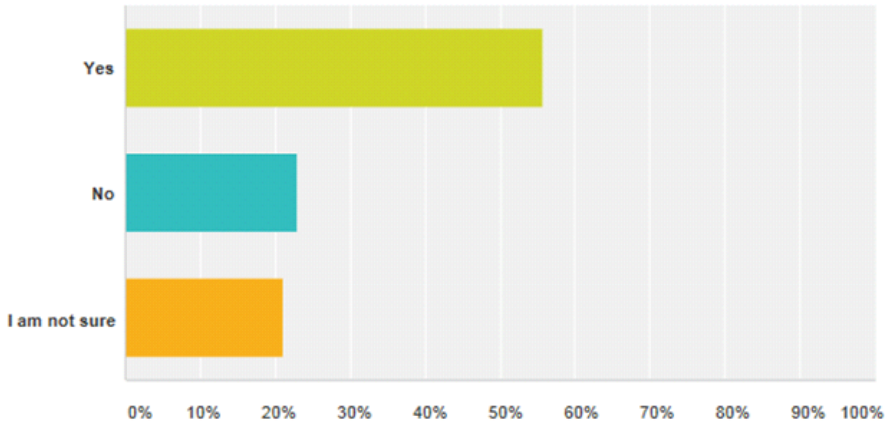
The survey asked whether any changes were required to the crisis care headings, subheadings and descriptions. This section describes the contentious issues which were identified from the textual responses and the decisions taken by the project team to address the issues. All of the following issues were discussed at the expert user group to gain consensus that changes were appropriate.

Person demographics	
ISSUE	**RESPONSE**
'Person alias' subheading was felt to be a judgemental term.	Description was updated. This was agreed to be an appropriate change by the expert user group.
'Ethnicity' and 'religion' subheadings should be added to person demographics.	The expert user group agreed with adding these subheadings to the 'person demographics' section as ethnicity can be

	important in identifying specific conditions such as sickle cell and religion in providing appropriate religious support.

Special requirements	
ISSUE	**RESPONSE**
Term ‘special’ was felt to be inappropriate.	The heading was amended to ‘individual requirements’. The expert user group agreed with the amendment and advised that examples were included for clarity.
Description was felt to be too vague.	The description was updated and agreed with by the expert user group.

Estimated prognosis
The survey asked whether it was appropriate to record information about ‘estimated prognosis’ in a crisis care summary. The results are presented below:



This was discussed at the expert user group and the decision was to include information about ‘estimated prognosis’ under the ‘crisis care plan’ heading, as it informs the care plan.

Diagnoses	
ISSUE	**RESPONSE**
There was lack of clarity about when to record diagnoses, problems and symptoms.	Description was updated and agreed by the expert user group. The word symptom was removed, so that only active current diagnoses should be recorded under this heading, with symptoms recorded under the problems and issues heading.

Medications and medical devices	
ISSUE	**RESPONSE**
Some subheadings were felt to be redundant: ‘medication status’, ‘reason for medication’, ‘medication	These subheadings were retained as they may be required in some instances. This was agreed at the expert user group.

recommendations'.	
Requests to add 'prescriber information'.	This heading is not currently included in the AoMRC/PRSB record standards. It would be complex to record eg in hospital where several clinicians may prescribe. It was discussed at the expert user group and the decision was that it was not necessary for a crisis care summary at this point, but may be added in the future.

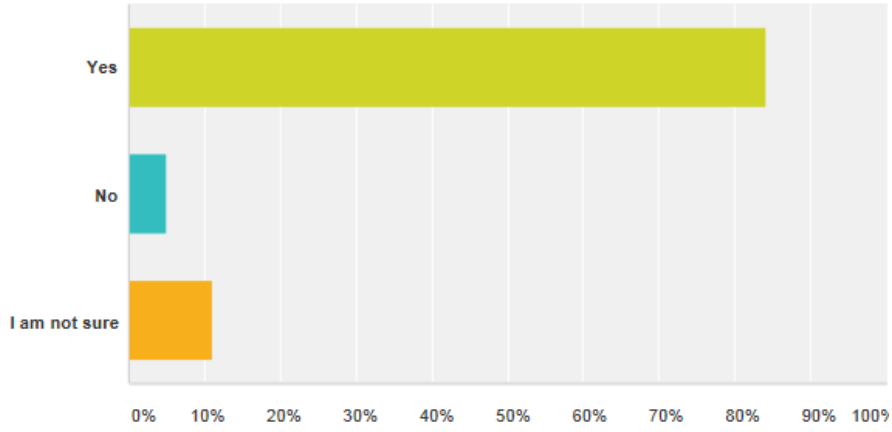
Allergies and adverse reactions	
ISSUE	**RESPONSE**
Request to remove some subheadings: 'certainty', 'evidence' and 'severity'.	These subheadings were removed. This was agreed at the expert user group as these would not generally be needed in a crisis care situation.

Safety alerts	
ISSUE	**RESPONSE**
The 'safety alerts' term was felt by some to be a judgemental term.	Previous consultations felt 'risks' was judgemental hence the change to safety alerts. The expert user group agreed that the term should be retained.

Legal information	
ISSUE	**RESPONSE**
'Mental capacity assessment' was felt irrelevant for a crisis care summary.	This was discussed at the expert user group and it was agreed to remove 'mental capacity assessment' but retain 'deprivation of liberty safeguards'.
'Consent for information sharing' needs to state the purpose and scope of the consent (eg consent to share crisis care summary).	Description was updated and agreed by the expert user group.
Debate whether to include 'CPR decision' as a subheading under the 'crisis care plan' or 'legal information' heading.	The expert user group advised that 'CPR decision' has no legal standing and so should be included with the 'crisis care plan' heading as it would be relevant to planning care.

Substance misuse

The survey asked whether it was appropriate to include a heading for 'substance misuse' in a crisis care summary. The results are presented below:



This was discussed at the expert user group and the consensus was that if relevant this information would be recorded under the 'problems and issues' section.

Crisis care plan	
ISSUE	**RESPONSE**
The 'agreed with person or legitimate representative' description was felt to be too vague.	Description was updated and agreed by the expert user group.
The 'priorities of care' description was felt to be too vague.	The description was updated and agreed by the expert user group. This subheading should align with the ECTP when it is finalised.
The 'anticipatory actions' subheading should include actions to be avoided also.	Description was updated and agreed by the expert user group.

Important headings
The survey asked which headings were of most importance in a crisis care summary. The results are presented below:

More than 90% of respondent felt the following headings were of particular importance:

- Person demographics
- Diagnoses
- Causative agent (allergy)

More than 80% of respondent felt the following headings were of particular importance:

- Relevant contacts
- Safety alerts

More than 70% of respondent felt the following headings were of particular importance:

- CPR decision
- Individual requirements
- Advance decisions to refuse treatment
- Medications
- Relevant past, medical, surgical, mental health history
- Problems and issues
- GP details