

Patient, family and health professional priorities for improving care and support in CUP

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‘Understanding the unknown’

- to explore key issues and experiences of living with CUP from the perspective of CUP patients, and from that of their family.
- to explore key issues and experience of caring for CUP patients, from the perspective of doctors and nurses.
- to work with CUP patients, their family, and health professionals to decide priorities for improving the care and support offered to those living with or affected by CUP

Phase 1

- Patients recruited from three NHS Trusts in southern England
- Eligible if ...
 - have a diagnosis of CUP or a diagnosis of metastatic cancer where no primary has been identified
 - are over 18 years of age
 - are able to give informed consent
 - are English speaking
 - are physically well enough to be interviewed
 - have a likely prognosis of at least one month

Phase 1

- Qualitative in-depth interviews with CUP patients, family members and health professionals identified by patients
- Interviews about their experiences of Cancer of Unknown Primary
- Interviewed 17 patients, 14 family members or friends, 13 health professionals
- Each case (patient, family member/friend and health professional) analysed thematically using a framework based on the stages of a patient journey.
- Cross-case analysis used to identify patterns and relationships among key themes and issues

Phase 2

- What are the most important support needs experienced by people living with CUP?
- Focus groups using nominal group technique to:
 - generate consensus, and
 - to prioritise between competing needs/demands
- Key themes/issues related to support needs derived from Phase 1 data, and presented to nominal groups
- They then identified which themes they thought most important

Nominal groups

- All patients and carers who were interviewed in Phase 1 were invited to take part.
- Health care professionals from Phase 1 augmented by asking HCPs to nominate colleagues who cared for CUP patients.
- 5 nominal groups: 2 with HCPs (11), 1 with patients (4), 1 with carers (2), 1 with patients and carers (3)
- 7 people completed the ranking and rating exercise by email/post as they were unable to attend a group (1 patient, 1 carer, 5 health professionals)

Statements of themes from
interview data.

A need for CUP and what it means to be explained

Patients and their carers often find CUP difficult to understand. They therefore need **the condition to be explained and what it might mean for them.**

They need this explanation when they are given a diagnosis that there is no evident

A need for a key person to co-ordinate the efforts of different HCPs

CUP patients will often see many different doctors, and may undergo many tests.

They therefore need to have an identified key person or champion within the health care system who will be responsible for

coordinating the efforts of different health care professionals

A need for a key person to give consistent information and support

Patients with CUP will often see a number of different doctors. They therefore need to have a key person (champion) within the health care system who they can turn to for **consistent information and support** about their condition.

A need for patients to understand reasoning behind investigations and tests

Patients with CUP often have many tests and investigations. They therefore need to **understand the reasoning behind each set of investigations and tests** and what these will tell doctors about their condition.

A need for early involvement of specialist palliative care services

There is great uncertainty with the outcome of a diagnosis of CUP. Patients therefore need **early involvement of specialist palliative care services**

A need to know everything appropriate has been done to find the primary cancer

Patients with CUP and their carers need to be sure that **everything appropriate** has been done to find the primary cancer

A need for information to understand more tests may not be the best thing

More tests may not be the best thing for CUP patients. Patients and their carers **need to have enough information to understand this.**

A need to know that HCPs have not given up or abandoned patients and carers

Throughout the CUP journey, patients and carers need to **know that health care professionals have not given up on them or abandoned them.**

A need for patients and carers to talk about causes of cancer

The primary site of the cancer may never be known. However, patients and their families need the **chance to talk about what might have caused the cancer**, and especially whether it might run in the family.

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A need for patients and their carers to know their needs are recognised and addressed

There is great uncertainty with the outcome of a diagnosis of CUP. Patients and carers therefore need **to know that their needs are recognised and addressed.**

A need to receive comprehensive written information about CUP

There is great uncertainty with CUP. Patients and their carers therefore need **comprehensive written information about CUP** to help them discuss their condition with their families and health professionals

Statement rating – top five statements

Statement

Need for key person to give consistent information and support	255/270	1
Need for key person to co-ordinate the efforts of different HCPs	249/270	2
Need for CUP and what it might mean to be explained	246/270	3
Need to know that HCPs have not given up or abandoned patients and carers	245/270	4
Need to know that everything appropriate has been done to find the primary cancer	242/270	5

Statement ranking – top six statements

Statement

Need for CUP and what it might mean to be explained	9 first choice 20 in top five	1
Need for key person to co-ordinate the efforts of different HCPs	5 first choice 17 in top five	2
Need for a key person to give consistent information and support	3 first choice 20 in top five	3
Need to know that everything appropriate has been done to find the primary cancer	3 first choice 13 in top five	4
Need for information to understand more tests may not be the best thing	2 first choice 5 in top five	5
Need to know that HCPs have not given up or abandoned patients and carers	1 first choice 19 in top five	6

Statements in top 6 for ranking and rating

Need for CUP and what it might mean to be explained

Need for key person to co-ordinate the efforts of different HCPs

Need for a key person to give consistent information and support

Need to know that everything appropriate has been done to find the primary cancer

Need for information to understand more tests may not be the best thing

Need to know that HCPs have not given up or abandoned patients and carers

Discussion

- Strengths and weaknesses
 - Health professionals mainly CNS (11 CNS, 5 other HP)
 - But CNS' across cancer sites
 - Small N patients and carers
 - But based on Phase 1
 - And other published patient data limited

Discussion

- NICE guidelines recommend cancer centre/units:
 - set up CUP teams to assess patients at referral and draw up management plan, including investigations, symptom control, access to psychological support and providing information
 - Assign a CUP specialist nurse or key worker to take major role in co-ordination, liaison with other services, stay in contact with patient and be their advocate
- Our findings support the need for these guidelines to be implemented.
- They help identify what teams and key workers should focus on

Patient (and family) centred care in CUP

- Make sure we know what CUP is, and what it might mean for us
- Make sure that one of you knows what the rest of you are doing and why, and can explain this to us
- Make sure that one of you keeps us informed about:
 - what is wrong with us,
 - what tests you want to do and why,
 - the results
 - and what happens next.

Patient (and family) centred care in CUP

- Make sure we understand why you think more tests won't help us.
- Make sure we know that you have done everything that is appropriate to do to find the primary cancer. And please make sure we understand why it wasn't appropriate to do more.
- This is tough for us – please make sure that as well as giving us information, you support us
- And we need to know that you haven't given up on us or abandoned us – and that you will not do so.