

**Pancreatic
Cancer
UK**



WPCCC Annual Meeting Supporting Pancreatic Cancer Patients Workshop

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- Introductions – objectives of the session:

To share learnings of pancreatic cancer service development

- Overview of the UK and PCUK services
- Deep dive into Living with pancreatic cancer days
- Questions and discussion

- Overview of Australia and Pancare Foundation's services
- Deep dive into Telehealth Pilot
- Questions and discussion

Pancreatic cancer in the UK

10,000

Pancreatic cancer cases
in 2016, UK



Pancreatic cancer is the **11th most common cancer**

9,000

Pancreatic cancer deaths in
2016, UK



Pancreatic cancer is the **5th biggest cancer killer**

7%

Five-year survival



Pancreatic cancer has the **lowest survival of all common cancers**

24%

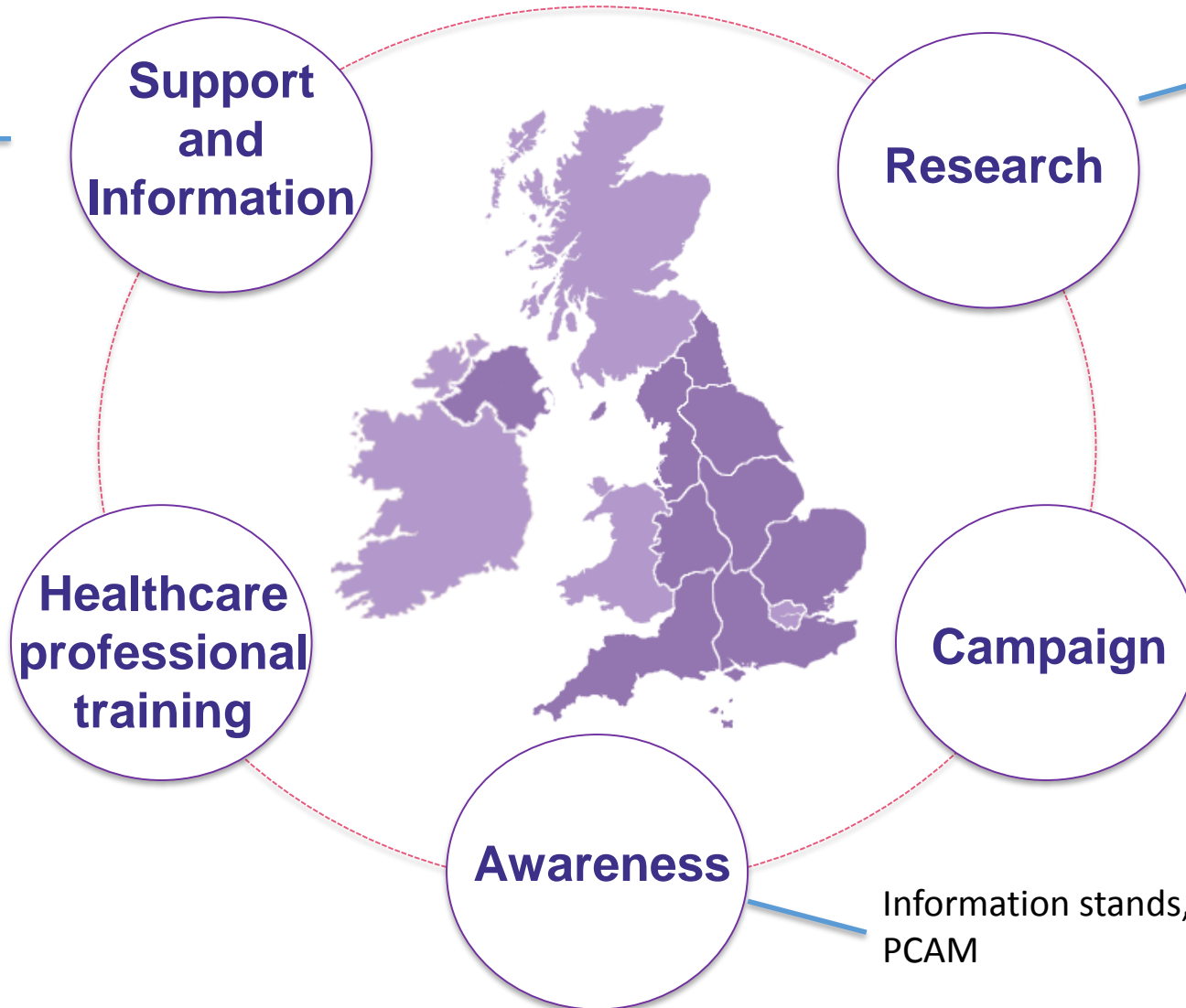
One-year survival



Pancreatic Cancer UK

Peer support, living with days, Supportline, online community, patient information

study days and annual national study day, annual summit



What we do

Research Innovation Fund
Early Diagnosis award
Future leaders Academy
Immunotherapy

transforming care,
NHS, UK policy,
public affairs

Information stands,
PCAM

2006

- **Charity founded** by Sue Ballard
- Patient Support and Research focussed

2015 - 2018

- **Living with Days** launch
- Abraxane Campaign
- New strategy: Taking it on together
- New 10 year research strategy
- Launch of Research Innovation Fund
- £1m research grant
- Launch Future Leaders Academy

2019 – Looking to the future

- **Expanding service reach**
- £10m investment to research
- **Digital services**
- Partnership / collaborations
- Improve care in NHS
- Pancreatic cancer pathway

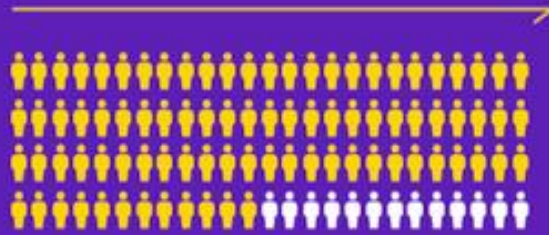
2010 – 2015

- Services development and reach
- **Support line opens & Nurses** recruited
- Expansion of range of information
- **Online community started**
- National Summit
- Healthcare professional training

2018 - 2019

- Demand Faster Treatment campaign and petition – 100,000 signatures
- Early Diagnosis £750k research investment
- **2000 individuals supported** through services
- **Side by Side launches**

Double
survival
rates



87%

of people reported that they have one or more supportive care needs



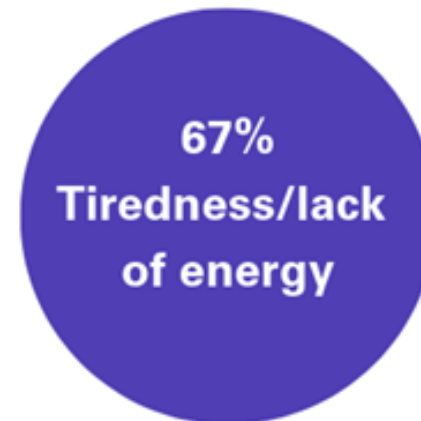
49%

reported one or more moderate or high unmet needs

Patient Survey:

274 people completed the survey

“
Two weeks after diagnosis, I still feel completely in the dark about what is going to happen
”



Inform by patients and carers

- Identify ways in which we can meet some of the support needs of pancreatic cancer patients through our own services and ensure more people are aware of our support
- Integrating the identified unmet needs within the survey results in the remit for our future Clinical Pioneer Awards
- Continue to lobby the Government and the NHS to ensure that the patient experience for people with pancreatic cancer is listened to and taken in to account in future work
- Sharing the results with the pancreatic cancer community – we need to work together to achieve change



Patient and Carer Advisory Board

- Feed into new service development
- Lay reviewing of info / info gaps
- Strategy development and input



Living with pancreatic cancer days

- **Empower** people to manage the symptoms and side effects
- **Improve** people's well-being – by providing information on **dietary related** symptoms
- **Help** people feel more connected – by bringing people **together**
- **Enable people** to access emotional and practical help
- **258** total number of people reached

Our learnings :

- An **informal** approach – being flexible throughout the day
- Working with **local team and CNS**
- **Partnerships** with other charities

Challenges:

- Peoples health
- Local reach
- Suitable venues

Pancreatic Cancer UK

“I think my Dad’s biggest issue is that he feels alone in his illness. By coming here (the Living with Day) he gets to meet others that understand everything he’s going through. I just wish there were more of them.”



Living with day feedback

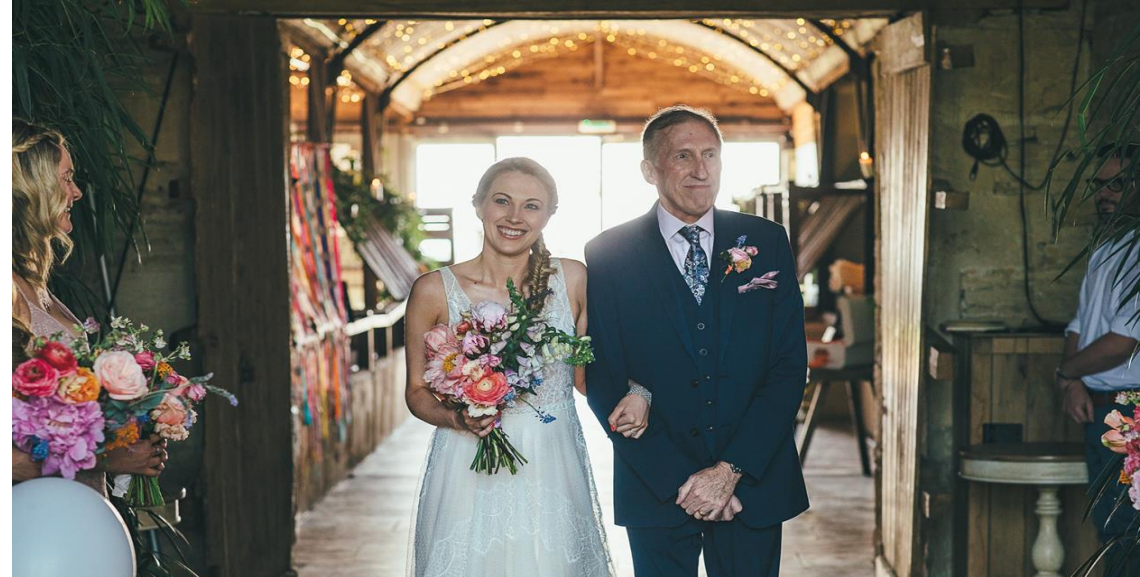


“The event was great. The organisers were friendly, kind and supportive towards everyone who came. They presented a lot of helpful information with booklets to take away. And being able to share our experiences and talk to other people affected by pancreatic cancer was invaluable”.

Pancreatic Cancer UK

- People have a **greater understanding** of pancreatic cancer and can make informed decisions about treatment and care
- People are able to **cope better** with the diagnosis of pancreatic cancer
- People feel **less alone** after meeting others in a similar situation
- People are able to **manage their symptoms and side effects** of the disease
- People are **aware** of other ways in which they can access **support and information**, both through PCUK and locally

Service evaluation



Q & A

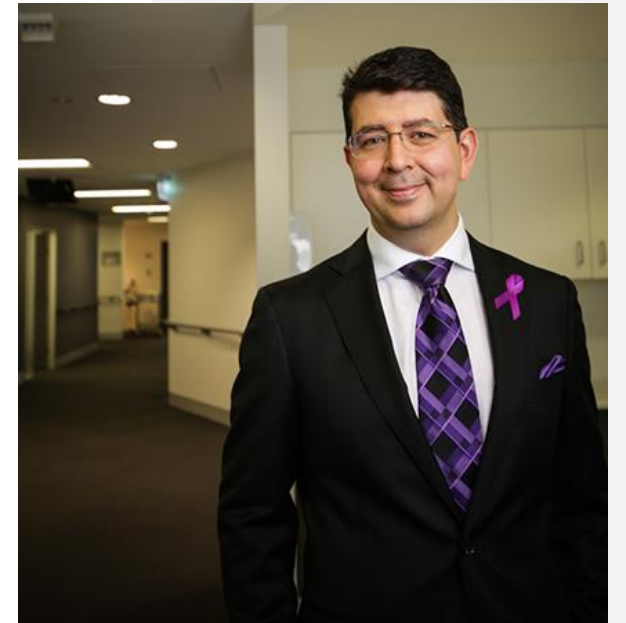


Let's rewrite the story

Established by leading cancer surgeon, Dr Mehrdad Nikfarjam in 2011, Pancare is a national not-for-profit organisation.

“I have dedicated my personal and professional life to putting a spotlight on pancreatic, liver and biliary cancers. To exploring new treatments that will improve the quality of life for patients and their families. To supporting the delivery of new research and clinical trials that will lead to less deaths and one day a cure.

The challenge is huge, but one that's worth the fight.”



The harsh realities

APPROXIMATELY

3,599

men & women

will be diagnosed with
pancreatic cancer this year

UP TO

3,051

men & women

will die from
pancreatic cancer this year

APPROXIMATELY

9.8%

Chance

of surviving past 5 years

5th most common cancer kill in Australia

11th most funded cancer in Australia

For 80% of patients the median survival is just 6 – 12 months

Australian Government: Australian Institute of Health and Welfare - "Cancer in Australia: 2019"

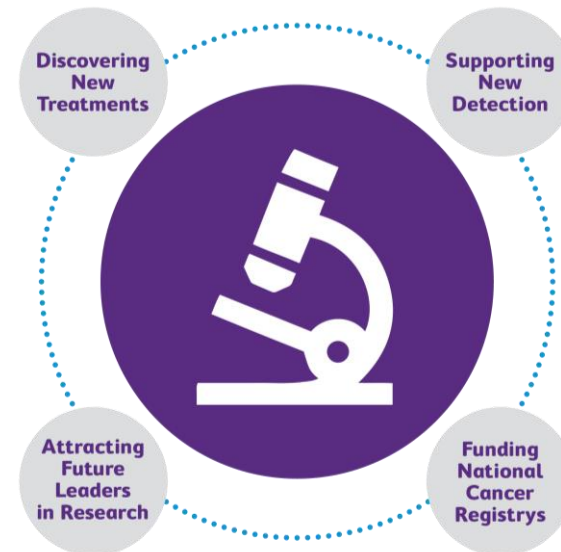
What we do

We're committed to delivering patient support services and to funding research that will have a direct impact on increasing survival rates for pancreatic and upper GI cancers.

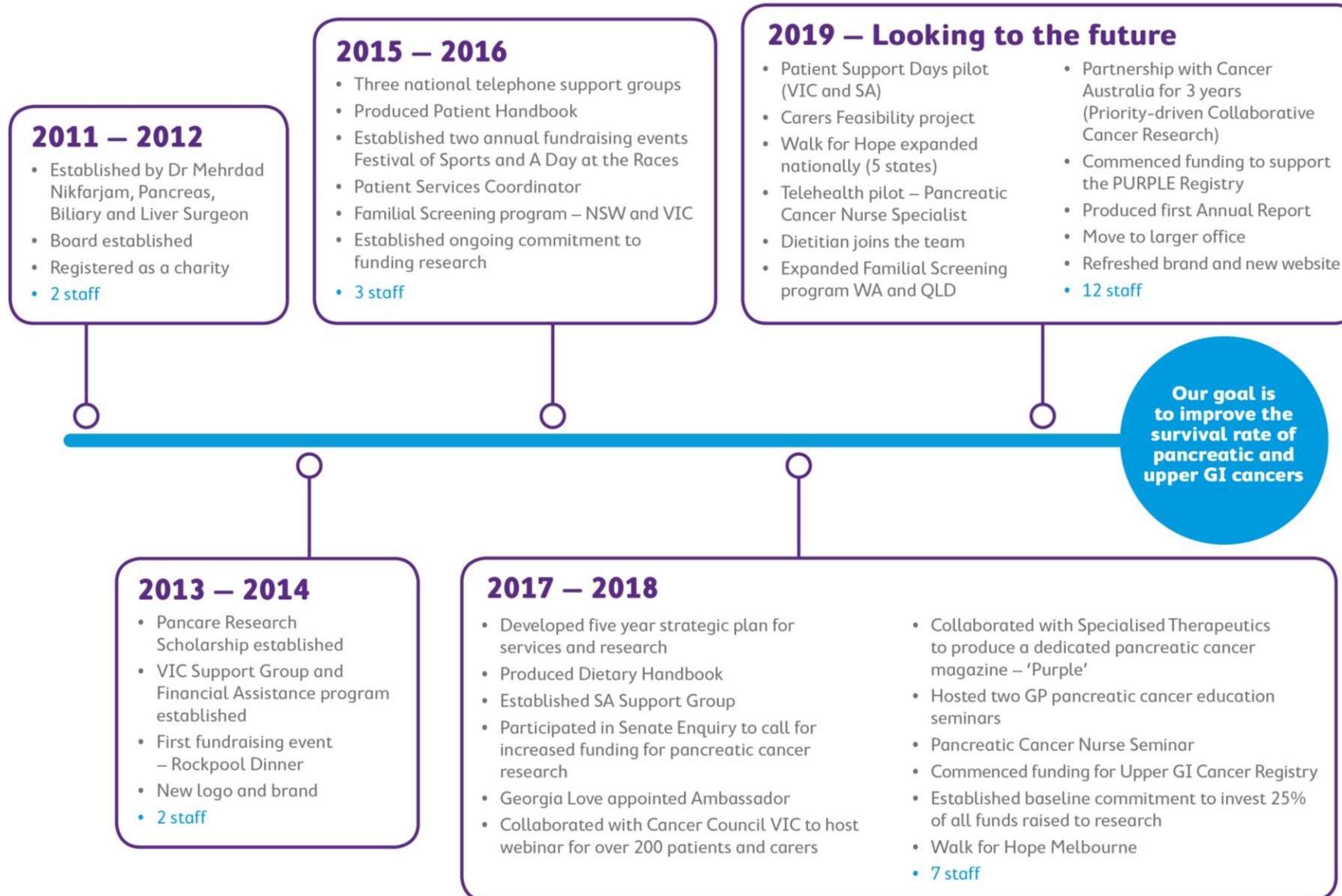
Delivering equitable access to our services that meet the needs of patients – no matter where they live.



Support research that has the best chance to improve survival and outcomes of pancreatic cancer.



Timeline

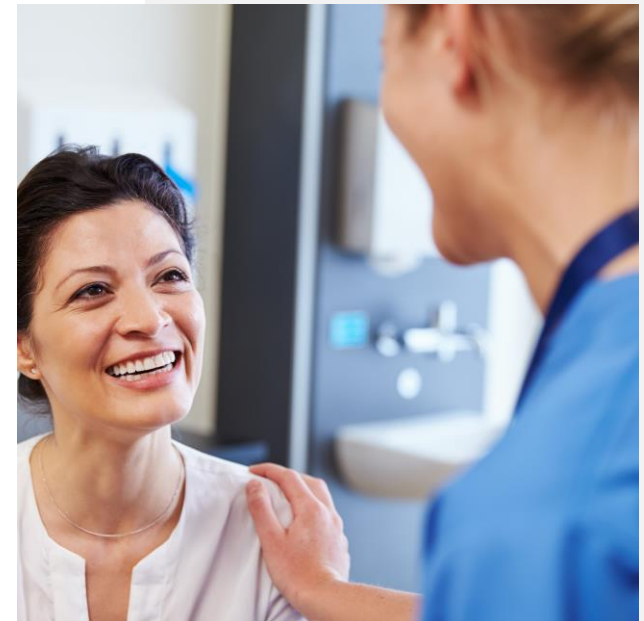


Patient Pathways Program - Telehealth Pilot

Pilot project will aim to set standards and a baseline in the way that patient organisations offer support, thereby building capacity within the health sector.

Background:

- ⑥ Centre for Community-Driven Research (CCDR) tested and implemented a Patient Pathways (Telehealth) model that can be adapted across disease areas.
- ⑥ Pancare invited to develop Telehealth for pancreatic cancer. CCDR are now referring all new patient enquires to Pancare.
- ⑥ Opportunity to not only support patients and their families but also implement a system to encourage community engagement and feedback in health and research.



Telehealth – what it delivers

Support to patients diagnosed with pancreatic cancer at all stages of their cancer journey.

Support provided:

- 6 Provide access to a pancreatic cancer nurse for one to one support
- 6 Help patients and carers to navigate the healthcare system and to access all the services that are available to them.
- 6 Support patients and their carers empowerment through education and information provision.
- 6 Support patients to proactively manage their condition or disease.
- 6 Support continuity of patient care with external healthcare organisations and facilities.
- 6 Support continuity of patient care with patients and their families following hospital admission, discharge or emergency visits and changes to their treatment plan.
- 6 Participate in data collection, health outcomes reporting, program evaluation and improvement related to the Patient Pathways pilot.



Patient Services model

Delivering equitable access to our services that meet the needs of patients – no matter where they live.

Meeting the needs of patients and carers:

- ⑥ National Telehealth Service providing access to Specialist Pancreatic Cancer Nurse, Dietitian and Patient Services Coordinator (case management team).
- ⑥ Continue to provide a personalised service.
- ⑥ Access to services in each state (Patient Support Days, Support Groups).
- ⑥ Information on Clinical Trials.
- ⑥ Pancreatic Cancer Nurse Network.
- ⑥ Provide information and support for any questions related to pancreatic cancer.
- ⑥ Information pack provided on point of diagnosis.
- ⑥ Joined up healthcare service provision for patients and carers



“Hope is passion for
what is possible”.



pancare
FOUNDATION

Q & A