

SCN Partnership Group

part of the NHS Sussex Cancer Network

Established for 10 years

**Working in Partnership
with Health Care Professionals
to improve cancer services**

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We have changed over the years

....and so has the Network

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Working in true partnership with professionals

**We no longer spend our time
trying to work out how to get
a voice.....we discuss how we
can best use that voice**

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**We make things
happen**

**we make things
better for patients**

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Being Involved

- patient support conferences
- new patient pathways
- surveys of new patients

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John Benstead

Diagnosed Prostate Cancer June 2004

Surgery Radical Prostatectomy Sept 2004

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John Benstead

**I joined the
Partnership Group
because**

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I joined the Partnership group because

The Reason -

- I was one of the mended ones
- I was prepared to show my gratitude by endeavouring to be helpful

*But there
needed to be
a*

Purpose -

I joined the Partnership Group -

- In order to make a difference
- So that I could help other patients and carers
- In order to help at the interface between the NHS, the patient and carer

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We gain Commitment through Involvement

For the
Patient:-

So much
to learn

- Can we understand how the NHS works
- Understand the Cancer Network Organisation
 - How to fit in
 - How to be accepted
 - How to be useful and contribute

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We gain Commitment through Involvement

The
High
Points:-

- The amount of Information, Acceptance and Support from the SCN.
- Becoming The Partnerships Member on CLAG.
- Attending the National Cancer Network Development Programme.
- This policy of inclusion by the SCN.

The Low Point:-

- As the Partnerships Member on FFF PRP.

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We gain Commitment through Involvement

My most
Interesting
and
Rewarding
Involvement:-

- Paul Johansons Macmillan funded
- Psychological and Psychiatric Support Services Steering Group Project.
- Without exception The Partnership Group supported the concept of this service provision.

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We gain
Commitment
through
Involvement.

It has been a pleasure
working with you.

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Carolyn Morris

I joined the
Partnership Group
because

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Why....

- *make things different*
- *quality, equality & coordination of care*
- *wanting to do something with the experience*
- *lots of motives!*

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How....

- *a notice – right time, right place*
- *people*
- *feeling you're being taken seriously*

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How I learned to love Peer Review

- *real involvement of people affected by cancer*
- *advances & supports user involvement elsewhere*
- *we are more than our disease*

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Margaret Ticehurst

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Partnership Group
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Visits

a working environment for staff

All new to the patient

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Centres of Excellence

Problems they can cause

So many things to consider

We do applaud 'best practice'

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Partnership Group

‘Awards for Excellence’

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John Davys

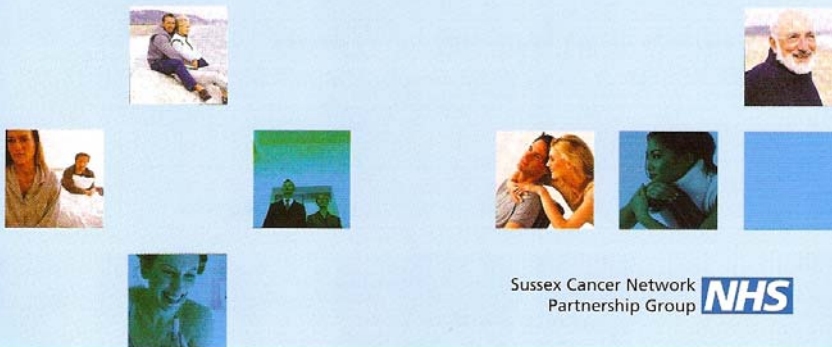
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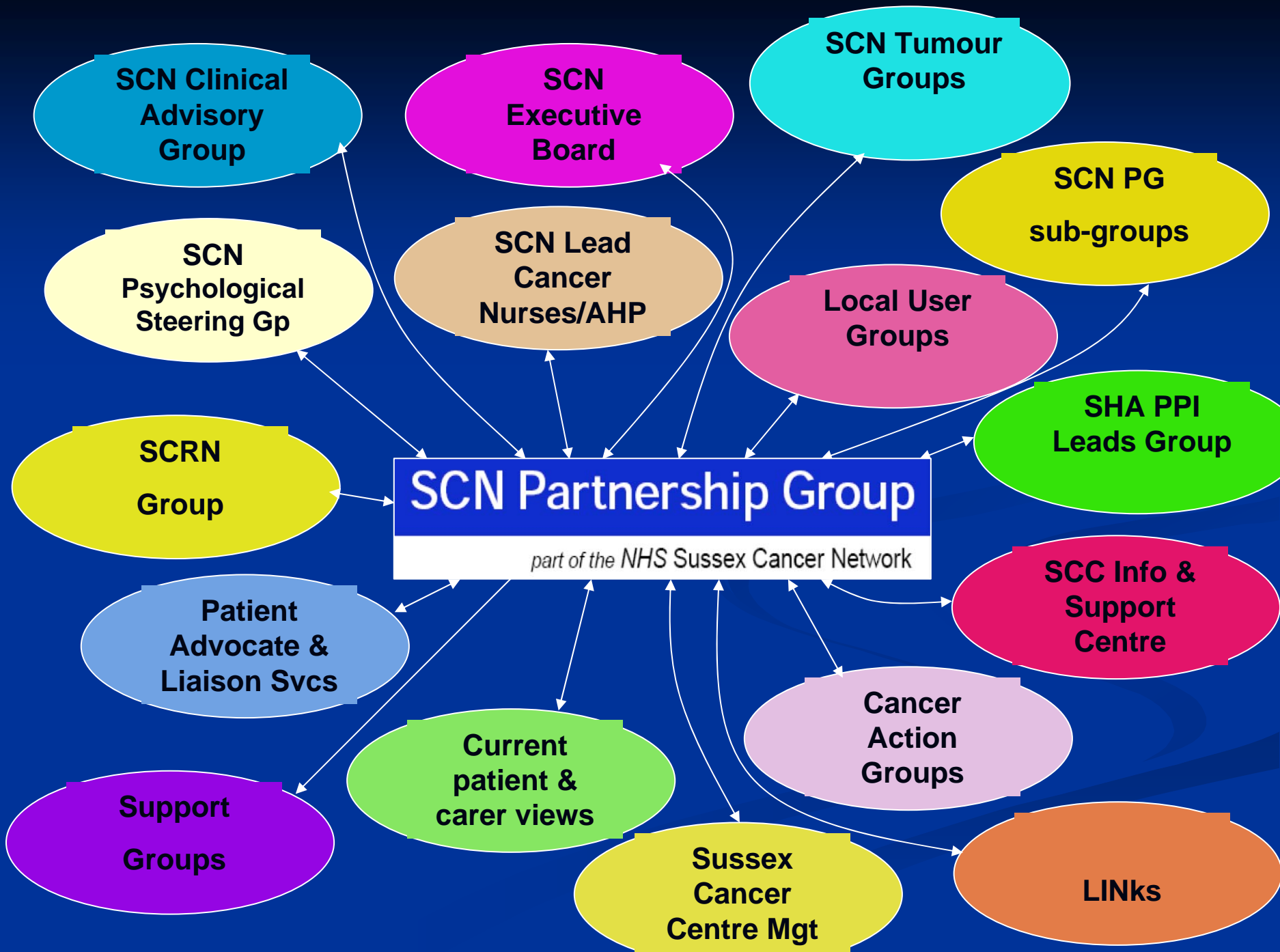
**Do You Want To Help Improve
Cancer Services In Sussex?**

Join

**The Sussex Cancer
Network Partnership Group**



Sussex Cancer Network
Partnership Group **NHS**



The fearful **The inarticulate** **The independent**

Elderly people living alone **Housebound**

Physically handicapped - blind, deaf, non-verbal, MS

Isolated women **Children and young people up to age 24**

Travellers and nomadic **Grieving** **Depressed**

Homeless **The disillusioned and uninterested**

The less well-educated

Those in institutions: **Low socio-economic groups**

Nursing & care homes, hospices, hostels, hospitals

Mental health sufferers **Rare cancers** **Learning difficulties**

Ethnic minorities **Those with English as a second language**

Those with different cultural experiences and expectations

Prison population

Drug addiction, dependency

Low income

Low nutrition

Low energy

Dementia

Those for whom Social Services are responsible

Listening to the Experts

*A summary of 'User Involvement in
Palliative Care: a scoping study'*



May 2008

Recommendations

- Recognise that we may all be “users” at some point
- Define “*current user*”
- Explore creative/novel ways to broaden involvement
- Dedicate resources
- Educate users and professionals
- Address organisational culture
- Research efficacy of user involvement from point of view of:
 - Patients and carers
 - Professionals
 - Organisations



Can we get you on Mastermind, Sybil?

Next contestant: Sybil Fawltly from Torquay

Specialist subject: The bleedin' obvious

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The Future

- **Meaningful involvement**
- **Planning and development**

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Help us to refresh

By encouraging new patients
and carers to join us

Partnership Group administrator
on 01273 545447