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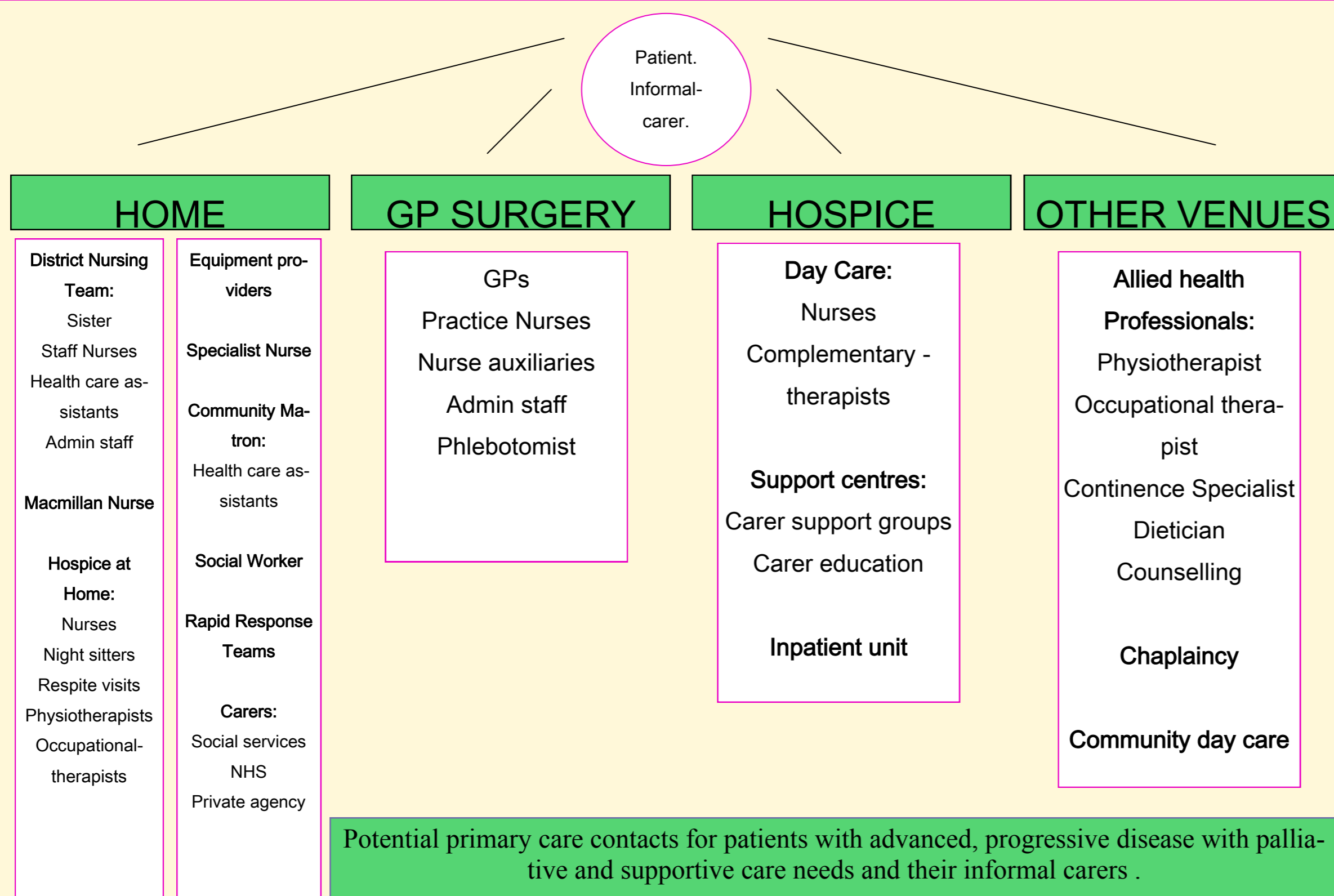
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Primary care palliative and supportive care services: Experiences and perceptions of patients with advanced progressive disease and their informal carers. A project summary.

PhD Research–Beth Hardy. Supervisors–Prof. Nigel King, Jan Firth, Alison Rodriguez.



Palliative care can be defined as the active, holistic care of patients with advanced progressive illness, and incorporates symptom management with psychological, social and spiritual care (WHO, 1990). Palliative care is for patients in the advanced stages of illness.

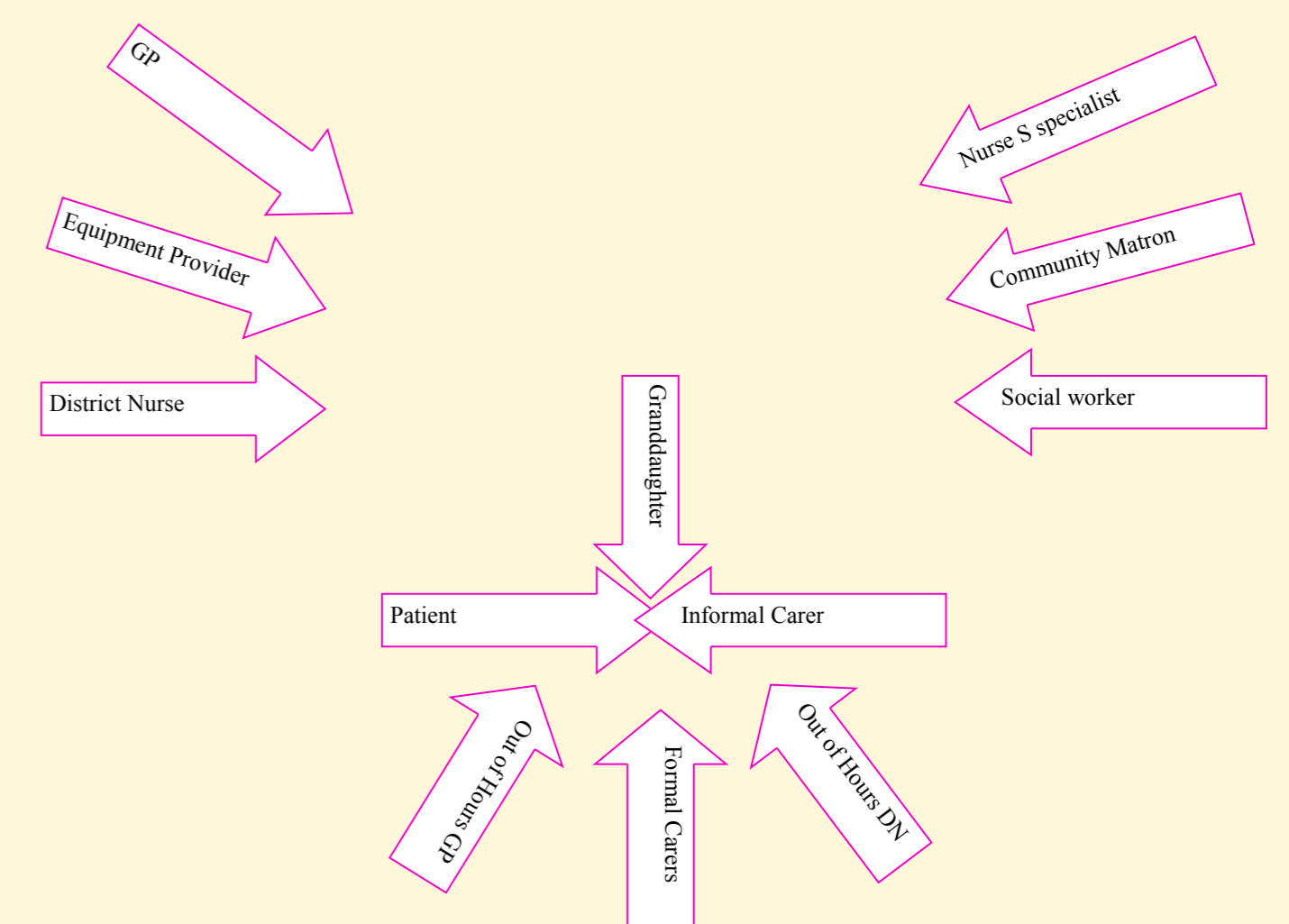
Supportive care follows people throughout the process of their disease, from pre-diagnosis, treatment, cure, continuing illness, death and into bereavement. The aim of supportive care is to maximise benefits of treatment and help people to live as well as possible with a disease (NCHSPCS, 2002).

The majority of palliative/supportive care is delivered in primary care, and up to 90% of people spend most of their last year of life at home (Aoun et al, 2005).

Palliative services were initially only available for cancer sufferers, however recent policy proclaims that palliative and supportive care services should be available to all, regardless of diagnosis (DoH, 2008) and a plethora of services now exist to meet these needs.

This research will take an interpretive phenomenological methodology to explore the experience of receiving these services from the perspectives of patients and their informal carers,

Example Pictor diagram done by a district nurse describing a case study of a patient with COPD in the last hours of life, and receiving care in the home environment.



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Aims

- To increase understanding of the experiences and perceptions of patients with advanced progressive disease, and their informal carers of receiving support from multiple primary care palliative and supportive care services.
- To explore how different care environments affect primary care contacts from a patient and informal carer perspective.

Method

- Two semi-structured interviews with all participants, held several months apart to see how experience and understanding changes as disease progresses.
- Interviews will utilise the Pictor technique. Pictor is a diagrammatic method of assisting people to explore and reflect upon networks of people. It involves asking participants to write down on separate pieces of paper all services that they have contact with, and then arrange these in a way that makes sense to them. It is a technique that has been used with great success with health professionals to describe their networks (King et al, 2008. Ross et al, 2005). Services users have been consulted on the use of this technique and very positive feedback has been received.
- Data will be analysed using the Template Analysis approach.

Sample

- Sample to be purposive. With a mix of disease, age and sex.
- Informal carers and patients may be recruited separately or together.
- 4 - 6 participants with cancer and their informal carers.
- 4 - 6 patients with organ failure and their informal carers.

Inclusion criteria

- Patients to have a progressive disease in the advanced stages, based on Gold Standards Framework guidelines. This could be cancer, heart disease, COPD, renal disease, Parkinson's disease, or multiple co-morbidities.
- Patient and informal carer to be aware of their diagnosis and that this is a progressive disease in the advanced stages. This will be confirmed by the health professional who refers them for inclusion.
- Patients must be receiving support from two or more palliative/supportive care services in primary care (excluding the GP).

Recruitment

- Participants to be recruited via the clinicians involved in their care. Potential participants will be given an information pack regarding the research, and will be asked to return a reply slip for further information if they are interested in participating in the research. The researcher will then make contact to discuss the research further before potential participants decide whether or not to participate.