

The James Parkinson Centre Cornwall

Creating a patient led NHS

Refining the patient journey



arkinson
Centre



James Parkinson Centre
Bringing people together to advance
Parkinson's disease care in Cornwall

THE JAMES PARKINSON CENTRE CORNWALL

The James Parkinson's Centre was formed by local people who had the desire to improve care for people with Parkinson's Disease (PD) across Cornwall. Our mission is to *'Bring people together to advance Parkinson's disease care in Cornwall'*

Parkinson's facts

- In Cornwall there are (using national estimates¹ and 2001 census results) around 1500 people with PD, Each Primary Care Trust (PCT) will have around 500 people with the disease who are supported by similar numbers of carers.
- Cornwall has a population of around 501,000 people, and based on these numbers in any one year there will around 55 new people diagnosed with PD of which 8-10 will be under 60 years of age, and a few will be under 40 years old when diagnosed.
- The cost of managing PD in Cornwall is estimated at around £8 million per annum.

The aims of the James Parkinson Centre Strategic plan launched 2003 are to:

Represent

The interests of individuals living with PD in Cornwall

Influence

Health and social care services in Cornwall to implement policy that improves the quality of life for people with PD in Cornwall

Develop

The skills and expertise of those involved in the care and management of people with PD professionally and academically

Build

Improved services for people with PD in Cornwall

Monitor

Services that are developed so that we can ensure their value

ACKNOWLEDGEMENT

The James Parkinson Centre is grateful to the many individuals who participated in the development of this work: Members from the Parkinson's disease Society branches of Mid Cornwall, Penzance and Bude, people with PD and their families across Cornwall too numerous to mention by name, professionals from the three PCTs in Cornwall, Richard Getliffe, Bob Kitchen and Ivan Lax from Catalyz who led the process mapping, Rosemary Maguire Mid Cornwall Branch PDS for her work on the questionnaire, John Sunmall for project co-ordination, Sheila Harvey George and Tricia Kent for help with proof reading and finally Sue MacMahon for drafting and editing this final report.

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EXECUTIVE SUMMARY

Parkinson's disease (PD) is the main neurological degenerative disease in older age after Alzheimer's Disease. In Cornwall, based on national data, there are up to 1,500 people living with PD and a similar number of informal carers. Health and social care for this group of individuals will cost the Cornish health economy around £8 million each year. In 2005 the James Parkinson Centre in partnership with the Mid Cornwall Branch of Parkinson's disease Society UK undertook an extensive consultation. This consultation received comments from over 250 people living with PD and representatives from each of the health and social care professionals caring for this group of individuals.

The NHS Improvement Plan (DH 2004) and Creating a Patient - led NHS (DH 2005) have indicated that the NHS truly wishes to create a patient-led NHS that responds to the needs and wishes of patients. This report therefore details findings from the consultation exercise and highlights several areas which people with PD found problematical and areas where services could be streamlined for greater patient benefit. In particular this includes the development of a self care programme, better use of the Single Assessment Process and use of IT for consultations so that automated workflow process systems are developed.

Recommendations are made for further work that would also refine service delivery.

INTRODUCTION

Care of people with chronic disease should be of prime importance to each health economy because of the opportunity to improve a person's quality of life and their journey through the health and social care system. Gaps in care delivery can quickly translate into quality-of-care concerns and reduced health care access. This report contains a short summary of work undertaken by the James Parkinson Centre Cornwall to process map the patient's journey for a chronic disease in Cornwall - Parkinson's disease. Whilst this mapping exercise has been undertaken in one disease area many of the issues raised and the benefits to be gained from addressing these issues would transfer benefits across other disease groups – "getting it right for one could mean getting it right for all".

The James Parkinson Centre wants to ensure that primary and secondary care providers:

1. Apply an individualised, whole-person approach to care of people with all interventions focused on promoting maximal function, independence, comfort, and quality of life.
2. Use primary care as the central organising force for health care across the continuum.
3. Provide care in the least invasive manner, in the least intensive setting.
4. Avoid adverse effects of medications and polypharmacy.
5. Use data to strengthen decision-making.

The JPC could assist PCTs to apply these principles to achieve their objectives in three areas that are critical to the success of the NHS Plan:

- Looking at the entire system from a patient's point of view and correcting the most serious gaps or duplications in the care pathway.
- Assuring care is delivered in the least intensive setting consistent with patient needs in order to use NHS resources to benefit the broadest group of NHS patients.
- Reallocating existing resources to new purposes rather than assigning new resources.

Scope

This project was initially developed to gain insight into the processes that supported the patient pathway through Parkinson's disease (from a patient perspective). There was a need to understand the high-level processes that support the patient journey through the four stages of the disease: **Diagnosis, Maintenance, Complex and Palliative Care** :

- how these processes interacted
- areas of concern
- where improvements could be made

As the work has progressed a number of specific disciplines and the processes that support them have been studied at the next level of detail and a number of process maps produced. These will be referred to later.

UNDERSTANDING PATIENT NEED - PROCESS

A questionnaire was initially circulated to PwPD and their carers across Cornwall to elicit their satisfaction with local health and social care services and to identify areas of need. Following this a series of focus groups were arranged that provided the opportunity to meet with and solicit opinion and choice on service delivery. Patients, carers and professionals in health and social care were consulted. 250 patients and carers participated.

This initial contact allowed us to gain some insights into what services were meeting patient need and where there were concerns from both patients and professionals. Building on this a number of more structured interview sessions were undertaken to gain further understanding of the processes being followed and how problems might arise on the patient pathway. Some of the learning from these investigations has been shared with participants in the study and further feedback received.

PROCESS MAPS

A number of process maps have been created to gain some insight of the overall relationships between the patients and the professionals, and the processes followed by a number of the professionals supplying services.

The Patient Journey through Health and Social Care in Cornwall

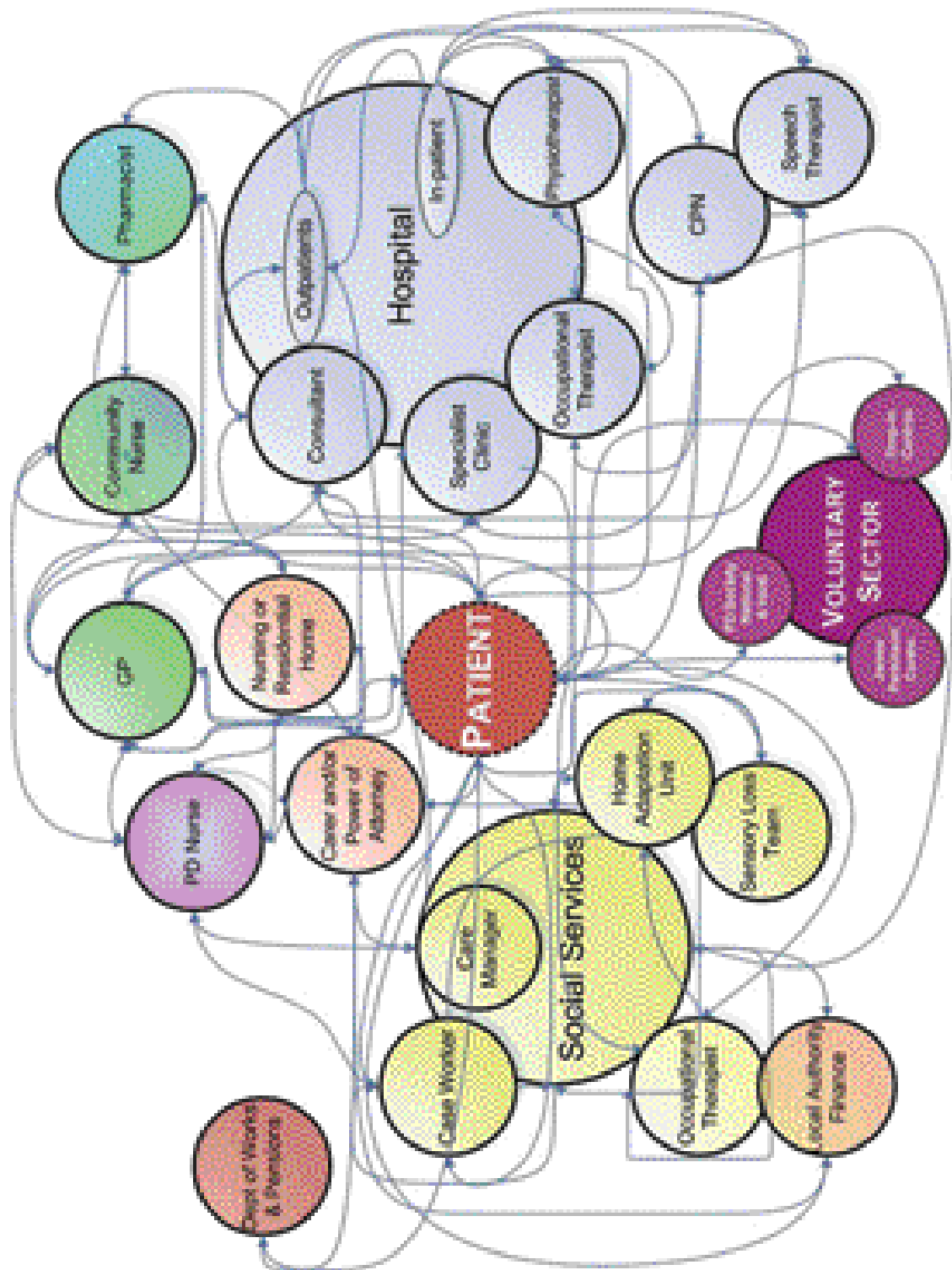


Figure 1

The diagram on the previous page was constructed to gain some perspective of the complexity of the environment in which a person with Parkinson's disease is cared for and the professionals that interact on the patient journey. It says nothing of the complexities of diagnosis or quality of service nor does it provide any insight as to the method of navigation within the system.

This diagram is not meant to be exhaustive but reflects the general environment and range of major services and suppliers for PwPD in Cornwall.

Diagnosis stage

To further develop our understanding of the system a number of examples were chosen for more detailed representation. The first process to be chosen was the initial diagnosis phase and the interaction between patient, GP and the secondary care consultant (Figure 2. Page 12), which still a somewhat complex begins to help us understand the flow of interactions involved in this first stage.

The time taken to complete this process can vary considerably based upon a number of factors including the availability of specialist resources. Individual process flows for a Physiotherapist (Figure 3. Page 13) and for a referral to Social Services (Figure 4. Page 14) were also prepared. Again in each of these diagrams a relatively high-level process flow is examined and this could be developed further. For example in the case of social services more detailed diagrams could show the process followed for referral to home adaptations, survey of a clients home, ordering materials and scheduling of work.

FINDINGS

During the course of the workshops and interviews a substantial amount of anecdotal views were collected based on individual experiences, particularly from patients. Rather than detail all of the opinions and data gathered from the various workshops we have summarised the major findings. (The full data is available as required). In providing this summary we have differentiated between feedback from patients and from professional providers as this may allow us to highlight some cause and effect relationships.

Necessarily, we do not focus on what is working well unless in the sense of an example from which we may learn and we will return to this in the recommendations section of this report. However, it should be said here that in general the level of satisfaction from patients in Cornwall was very high and reflected the special efforts that have been made in the region.



PATIENTS

Areas of concern that were highlighted by patients have been categorised using the four areas. These were:

Diagnosis:

- There is a lack of General Practitioner (GP) knowledge on Parkinson's disease (PD).
- There is a lack of information on PD in GP's surgery.
- There are issues with the time taken to diagnosis from the initial GP consultation for example delays may ensue if the likelihood of PD not recognised and classed as problems of older age, stress. Further delays may result because there is no simple test to confirm the diagnosis (as with diabetes)

Maintenance:

- There is no apparent automatic referral to specialist support for people with PD e.g. the Parkinson's disease nurse specialist (PDNS).
- There is no easily discovered information about availability of the PDNS or other nursing and therapy specialists that may be needed e.g. continence nurse specialist
- There is the possibility of 'fall out' from the health care system once a treatment package has been arranged.

Complex:

- The management of medication on admission and discharge from hospital is problematical. Hospital drugs administration routine overrides individual timetables for medication - a critical issue in PD.
- There is a general lack of advice about the complex medication needed for PD particularly where there is a dispensing surgery with no pharmacist on duty to give advice.

Palliative:

- There is fragmentation of different services; health and social care.
- There is lack of contact with PDNS.

Professionals

Turning to the concerns and issues raised by the various groups of professional who attended the workshops, made individual submissions or agreed to interviews, the following issues were raised:

- Communication problems, unresponsiveness, and lack of cooperation between the professions, i.e. no tracking of referrals, repeat requests for information ignored, lack of access to patient records by other professionals and those held by the GP.
- Inconsistency of processes. Despite the introduction of the Single Assessment Process this is not generally used and inconsistencies still occur.
- Workload. Case load demand is high, particularly for the PDNS, and almost all complained of insufficient time for training and research.
- Access to training. Whilst more training is being made available, this puts more pressure on overburdened schedules. Recognition of the need for training by management is essential.

Looking at the issues raised by the professionals we can immediately see a causal relationship with some issues raised by patients.

WHAT HAS BEEN DONE SO FAR?

In recognition of the problems identified, the James Parkinson Centre has developed and supported several initiatives, some of which are in partnership with the local branches of Parkinson's disease Society (Mid Cornwall, Penzance and Bude) and the local PCTs.

- JPC supported by West of Cornwall PCT has a central point of contact for people with PD at Camborne Redruth Hospital.
- JPC has supported additional hours of PDNS cover in West of Cornwall PCT to ensure there was more specialist nursing access for PwPD
- JPC has, in partnership with the PDNSs in Cornwall developed and funded a managed clinical network of professionals with a special interest in Parkinson's disease. Over 150 professionals are now registered with this network and they meet four times annually for educational training in all aspects of PD. This has ensured more staff have the skills to manage PwPD and their carers. This initiative has been highlighted as an example of good practice in the National Service Framework for Long term Conditions Good Practice Guide (DH 2005)
- JPC in partnership with Mid Cornwall PDS has developed Drop in Centres for people with PD. These are held on a monthly basis throughout Cornwall in Camborne, Torpoint, Truro, St Austell and Pensilva. These centres provide valuable psychological support, information and a social outlet for PwPD and their carers. The Drop ins have numerous local partnerships: e.g. in Truro partnership with an educational provider Truro College; Mid Cornwall PDS for volunteer and financial support and the Rotary Club of Truro for funding and volunteer support. Other Drop ins have similar supporters.
- In Truro the Drop in centre has a carer support group running alongside
- JPC in partnership with Central Cornwall PCT developed a pharmacy project that provided an at home medication assessment by a community pharmacist. This project highlighted several medicines management problems that people with PD face from simple issues like inability to open blister packs of medication to PD drug incompatibility that had not been recognised.
- JPC has supported the development of a General practitioner (GP) with special interest (GPSI) in PD in the West of Cornwall PCT. A Parkinson's Charter was developed by the World Health Organisation (WHO) in 1997 and an audit based on these WHO standards has been undertaken in the West of Cornwall by the GP to inform future service delivery.

The Mid Cornwall branch of PDS has also developed:

- An information postcard with contact numbers for the local PDS and PDNS clearly visible
- A newly diagnosed with PD in Cornwall pack which includes a book for the newly diagnosed written by a local person with PD
- An 0800 phone number for support for PwPD
- A support group for younger people with PD
- A information newsletter
- A welfare officer post so that PwPD have a local source of support.
- An information CD is also in progress

These initiatives start to address many of the problems identified from our process mapping but further work needs to be undertaken.

RECOMMENDATIONS

Much of what has been observed and reported from the process mapping would require a concerted effort by a number of groups within Health and Social Care to create a single unified system for PD. This would involve a greater integration of information systems and a level of coordination of resources across agencies and budgets, Benefits resulting would have a knock on benefit for other chronic disease areas.

Much could be done at a lower cost that would address the major issues raised by the patients. These activities have been arranged under the following headings:

EDUCATION

There is a distinct lack of education material available on the topic of Parkinson's disease at a general practice level. When compared to the wealth of leaflets on such topics as vaccinations for foreign holidays, heart disease, blood pressure, smoking cessation and diabetes there is very little or nothing available on PD. PD is not a priority in primary care but having a GPSI in one PCT has been beneficial for GP education and development. This further encourages services to develop 'closer to home'.

WHAT COULD BE DONE

- It would appear a simple matter to have in each GP surgery and health care establishment an easily readable leaflet outlining the PD conditions, the diagnosis process (and the challenges it presents), as well as addressing some of the areas below such as local support contacts.
- GPSI posts for PD should be developed in Central Cornwall and North and East Cornwall PCTs

AVAILABLE SUPPORT

In a similar vein to education there is little easily accessible documentation on the type and availability of support services for people with PD. Specialist drop in centres developed by the James Parkinson Centre and Mid Cornwall Branch of the Parkinson's disease Society exist but many patients and GPs have no knowledge of these. Once discovered they prove a relative 'goldmine' for patients.

WHAT COULD BE DONE

- As in item 1 above detail of available support services, contact telephone numbers and guidelines on eligibility could be included in a single PD education leaflet. This could be done in a templated form to accommodate local variances. Further 'Drop ins' should be developed as funding and resources allow. Falmouth area would be the next priority area for a Drop in.

TRAINING

Improving the knowledge of PD, new developments and local specialist resources and training events should be high on the list of developments.

WHAT COULD BE DONE

- The PD Managed Network days developed in partnership with the local PDNSs are invaluable and as most professionals now have access to internet and email services a professional's knowledge website could be created supported by a newsletter. For PwPD self care training is a priority. Cornwall has already benefited from the Expert Patient Programme held exclusively for people with PD. This course whilst beneficial needs to be further developed into a more comprehensive self care programme that addresses self care across all disease stages of PD.
- A self care educational programme is developed for PwPD by individuals who currently live with the disease themselves.

SERVICE DELIVERY

In addition to the three items highlighted above, all of which are relatively low cost the area that should be urgently reviewed concerns the use of the Single Assessment Process. The copy of the SAP made available to JPC for the purpose of this exercise is dated April 2003. This is presented as a joint document by the NHS Cornwall Health Community and Cornwall County Council Social Services. There is obviously a need for this and some investment has been made in the creation of this process and documentation. The questions must therefore be asked; why it is not being used throughout both services, and what changes must be made to remedy this? **We would recommend an urgent review of this process to ensure the SAP is better utilised.**

Returning to the question of greater integration and cooperation and the use of IT systems to support professionals in Health and Social Care: much could be done to monitor, track and automate the workflow processes across the system. This could include the use of electronic data capture, workflow automation and patient tracking. Such a system could allow for a level of self-management by PwPD to access the system and check their own progress through the system. However, as previously indicated this would require a level of integration much greater than exists today and a real desire to make this work. **We would recommend that an outline investigation be made of the implications of such a plan that could be presented to the interested funding bodies to assess the level of commitment.** With current initiatives in the provisioning of e-services this approach would seem to reflect the medium to long-term aspirations of the Government.

CONCLUSIONS

Much excellent work is obviously being done in Cornwall and this is reflected in the views of many patients and professionals. The role of the PD Nurse, the joint training initiatives and projects such as the Community Pharmacist work are excellent examples.

Much more could however be done at a relatively low cost. Equally, priorities need to be set around other demands and the ability to execute more ambitious options involving integration of IT systems.

Providing timely and relevant information to patient, carer and professional is the priority of all concerned and the recommendations given here, based on the practical day-to-day experiences of both groups, go some considerable way to ensuring this.

REFERENCES

- Department of Health 2004 The NHS Improvement Plan HMSO London
- Department of Health (2005) Creating a Patient – led NHS HMSO London
- The James Parkinson Centre (2003) Strategic Plan JPC Cornwall
- The National Service Framework for Long term Conditions (2005) HMSO London

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Patient Referral and Diagnosis Process

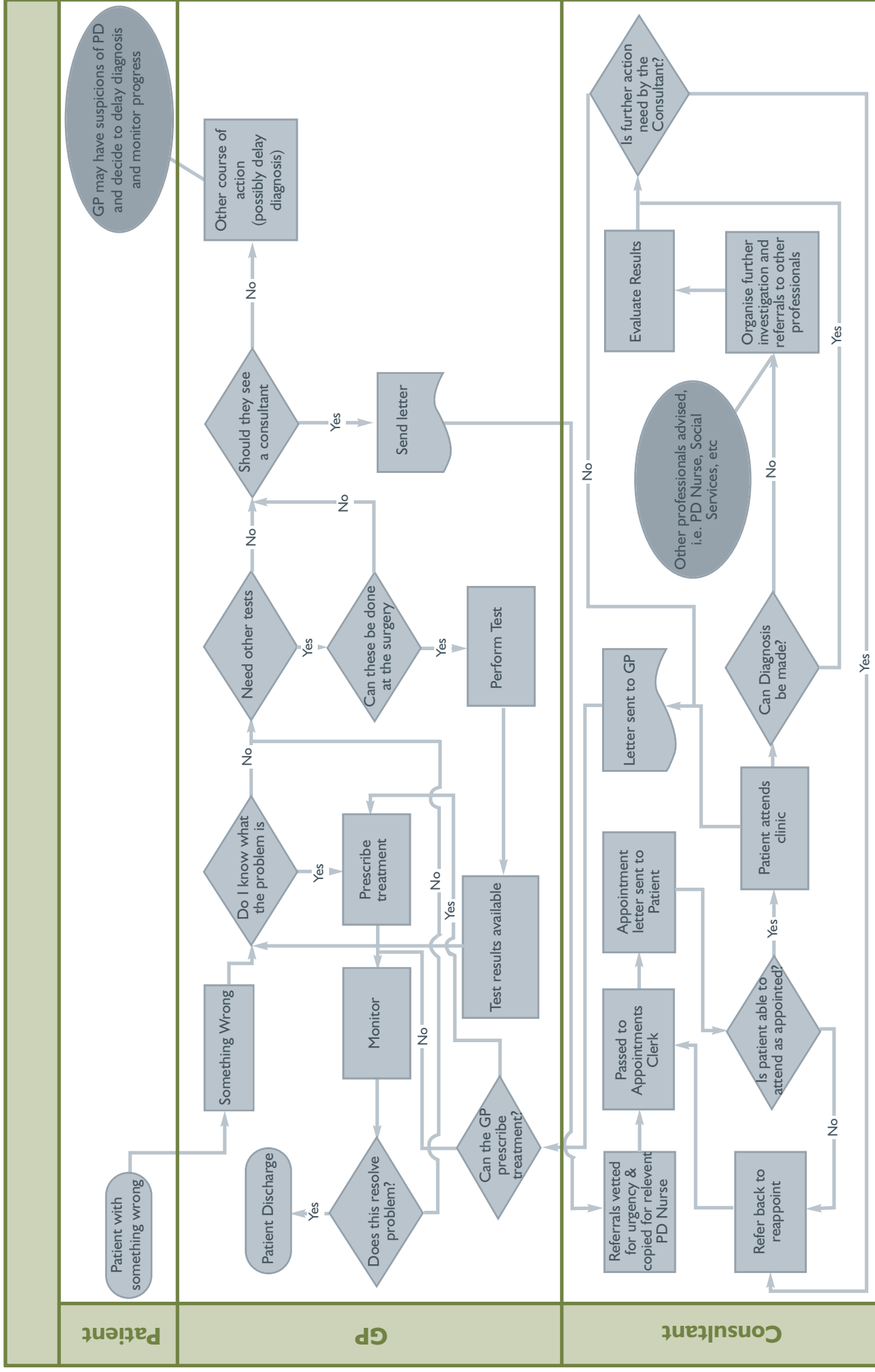


Figure 2

A referral to a Physiotherapist

- A referral to the Physiotherapist can come from many sources:
1. GP
 2. Consultant
 3. In-patient status
 4. Out-patient status
 5. other Health Care professional
 6. Social Services

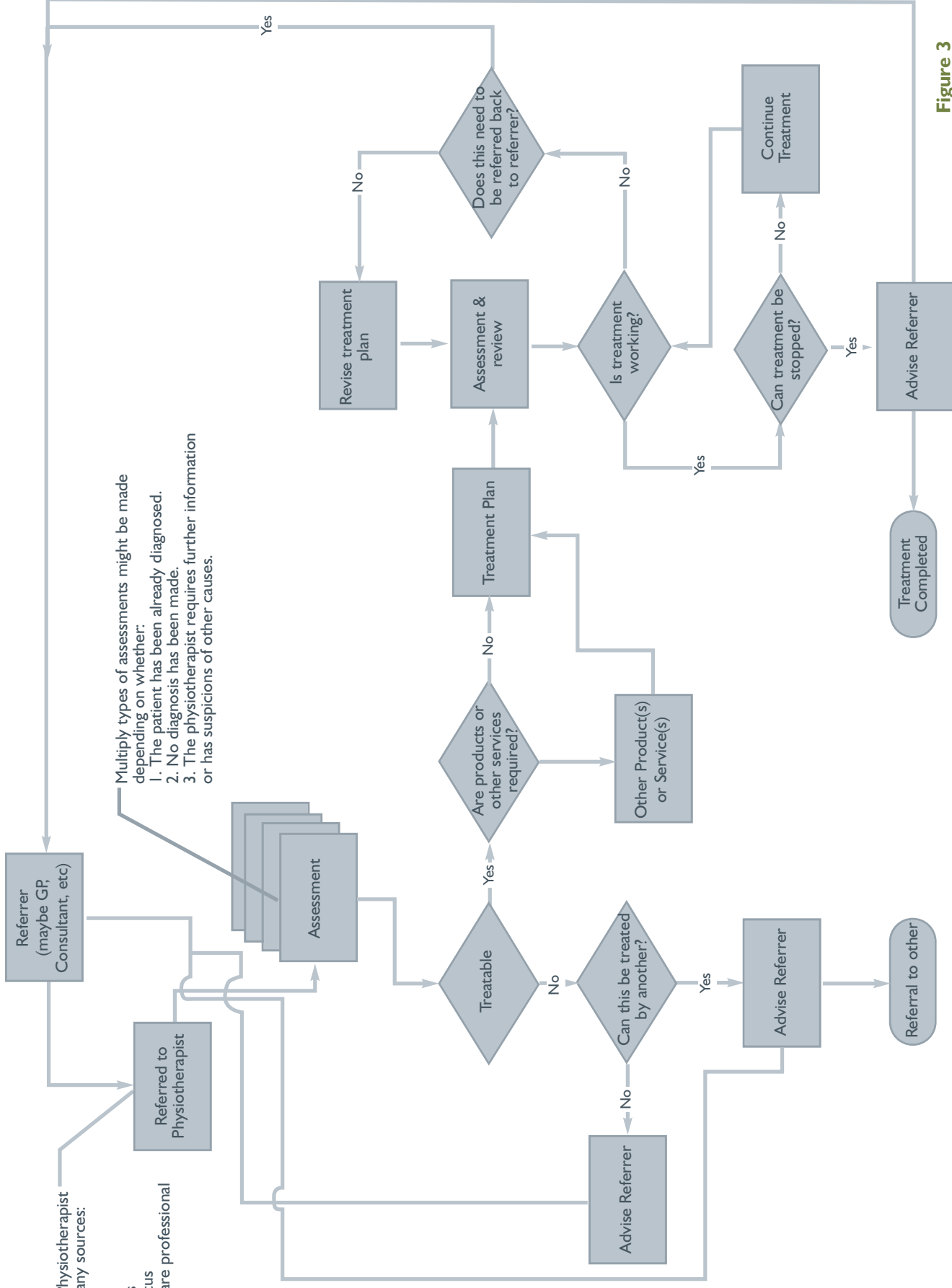


Figure 3

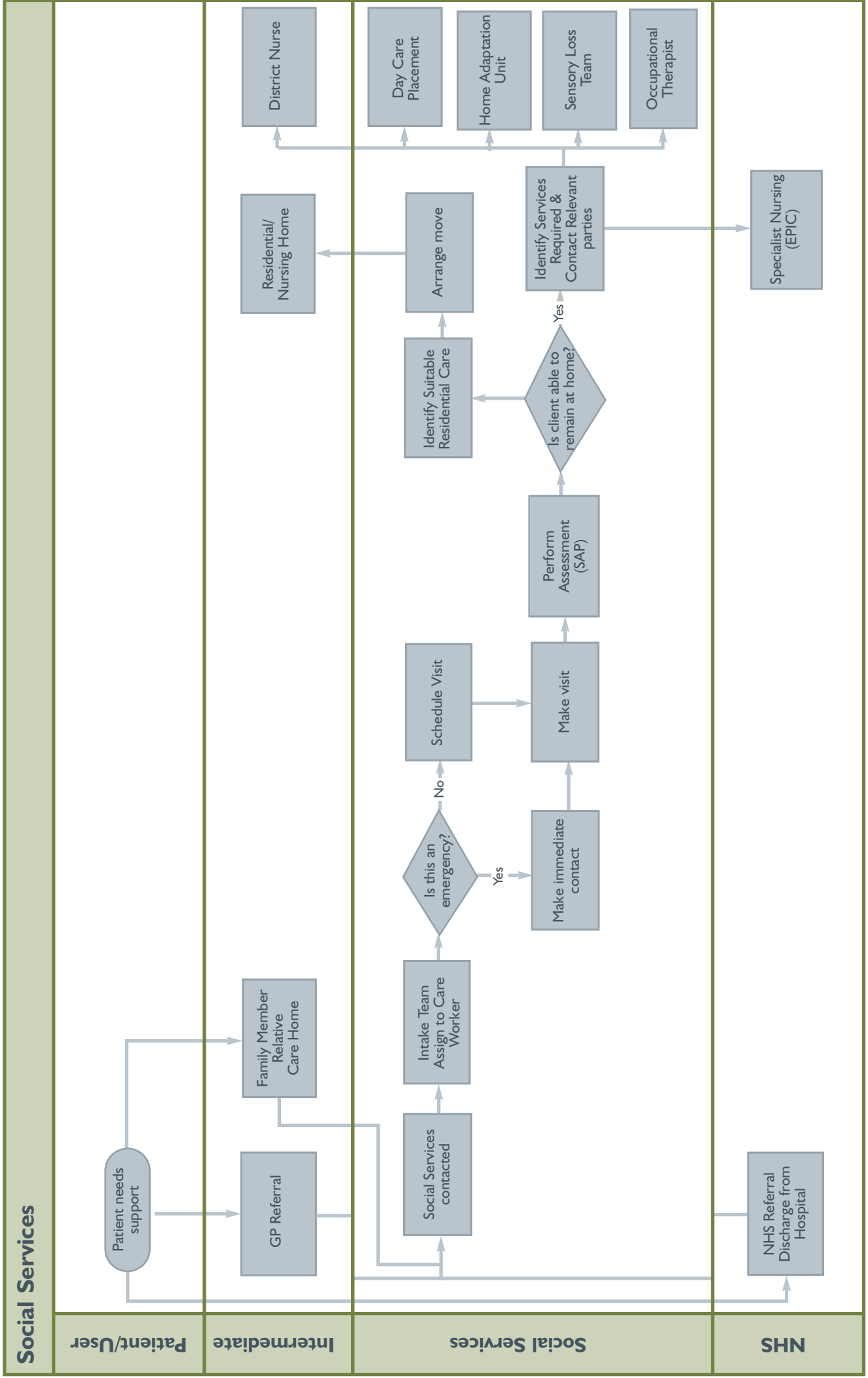


Figure 4



Contact in Cornwall for Parkinson's disease

James Parkinson Centre
01209 88160

Cornwall PDS Branches
Freephone 0800 1077954

Parkinson's disease nurse specialists

West of Cornwall PCT
01736 575577

Central Cornwall PCT
01726 627896

North and East Cornwall PCT
01579 335389

PDS UK
0207 931 8080
www.parkinsons.org.uk