

# Lymph Node Pathway Patient Feedback

Feedback from semi-structured interviews Final  
Report as of 29<sup>th</sup> June 2023

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## Introduction

### Context

This report relates to, and forms a sub-project of, the Lymph Node Pathology Pathway pilot (LNP). The aim of the pilot is *"To design, pilot and evaluate a 2WW (2 week wait) referral pathway for patients with lumps or bumps who do not fit existing pathway referral criteria. This will be the Lymph Node Pathology (LNP) and this patient cohort will form part of the non-specific symptom patient cohort in line with national team recommendations"*. (Ref - Project Initiation Document). The pilot is currently being held at University Hospitals Dorset NHS Foundation Trust (UHD) with a view to expanding to Dorset County Hospital NHS Foundation Trust (DCH) and Wessex Wide at a later stage.

### Service User Engagement Proposal

Full details of the Service User Engagement Proposal are available in the document "Lymph Node Pathology Pathway Pilot: A proposed approach to public, patient and carer involvement (Final Nov 2022)" which detailed proposals to:

- Undertake 20 in-depth service user semi-structured telephone conversations to inform the final agreed pathway. Involving People (IP) (formally Wessex Voices) to carry out the conversations on behalf of the service.

This focused work will provide an understanding of how the first service users to go through the pathway feel about their experience, to provide:

- a baseline for quality improvement
- information to support the development of the pathway

This report documents the feedback from the interviews undertaken.

## Methodology

Full details can be found in “Lymph Node Pathology Pathway Pilot: A proposed approach to public, patient and carer involvement (Final Nov 2022)”, to summarise:

- At patient/service user biopsy, Cancer Nurse Specialist (CNS) introduce the concept of the feedback conversation and requests verbal consent to pass details to IP. Service users are provided with a Patient Information Sheet (see proposal document).
- The CNS/Navigator records consent on EPR notes.
- After appropriate filtering, CNS/ Navigator shares consenting service user details with IP (encrypted).
- IP calls service user. (Note, IP will only attempt to schedule conversation 3 times), following an agreed script (covering consent. GDPR etc)
- Interviews are audio recorded (with consent), transcribed verbatim, analysed, anonymised and themed.

Questions for service users:

1. When your GP referred you to the Lymph Node Pathway service, what information were you given and did it explain why you were being referred?
2. Can you tell me about the experience of your first phone calls with the Lymph Node Service. After scan but before biopsy.
3. Can you tell me about your experience of having your tests organised?
4. Can you tell me about your experience of going to have your tests?
5. After you had your tests, what were you told about what was going to happen next?
6. What other information and support did the Lymph Node Pathway service give you?
7. Overall, how do you feel about how you were looked after by LNP team?
8. Demographic questions - gender, age, ethnicity, whether user has long-term condition or disability.

## Findings

As of 29<sup>th</sup> June 2023, 13 service user details have been passed to IP. Of those:

- 9 interviews complete.
- 2 users no longer wished to be involved.
- 2 have not responded to emails and/or calls.

Completed Interviews:

Patient demographics:

ID	Gender	Age	Ethnicity	LTC/Other conditions
0001	Male	81	White British	Yes
0002	Male	54	White British	No
0003	Male	40	White British	No
0004	Female	77	White British	Yes
0005	Male	76	White British	Yes
0006	Male	80	White British	No
0007	Female	83	White British	Yes
0008	Male	38	White British	No
0009	Male	53	White British	Yes

## Results of Interviews

Main bullet points:

### Service user ID 0001

- Struggled to remember the service as something separate as he's "in and out of hospital a lot".
- Went to GP as he was concerned about a lump (he has had issues before).
- GP referred him to the service. Only about a week before he went in (Poole).
- No written information or anything but he doesn't think it would have helped as he knew what to expect from previous experience.
- Can't remember if he had a call about the appointment or a letter (again due to the number of times he is in and out and the number of letters he gets due to other conditions etc)
- Felt it was very efficient and very quick - didn't even wait long in the waiting room for tests. Can't remember if he talked to a CNS or anything but remembers being taken through to the GP by a nurse.
- Tests and scans were very quick - about 10 minutes. Was told at the time that they couldn't find anything, and a report would be sent to his GP.
- Has not seen GP since that time so is not clear about what happens next. He is assuming all is OK. Nothing received in writing Again - can't recall any calls from CNS but was quite confused about this service as something different.
- Can't recall being given any further information from the LNP service, although he doesn't think it would have been helpful at that stage.
- Feels there's nothing that could have been done better.

### Summary

Gentleman quite confused about trying to differentiate this service from others. However, he had no issues or concerns about any of the treatment or care received.

**Service user ID 0002**

- Was already in Bournemouth hospital so not referred via GP. Advised he was referred to LNP via the Jigsaw (?). At time of conversation he was awaiting a diagnosis.
- He wasn't really told what the LNP is - they just referred him and he feels it was just part of the treatment he was getting while there. Wasn't really told it was a different service or pathway so there was no explanation (that he could remember) of what the LNP service was. He was just told he needed more tests as they had found a lump.
- Didn't remember receiving any calls from the LNP service.
- Tests done quickly, all whilst he was in hospital, and he didn't have to go back for them which he felt was very good.
- Didn't think there was anything that could have been done differently apart from the discharge from hospital process. He had to wait a long time for medication and paperwork to be done. Had to have taxi home. Couldn't stay at/by bed while waiting.
- Currently waiting next set of tests.
- Doesn't feel that any further information would have been helpful really - he just "relies on the nurses to do what needs to be done".
- Feels there's nothing that could have been done better.

**Summary**

Gentleman could not remember having any separate calls or conversations with specific staff/CNS from LNP.

**Service user ID 0003**

- Went to GP who explained about the referral to LNP - it was done via an emergency appointment, and he was in for tests in Bournemouth within days (attended both Poole and Bournemouth for tests and biopsy).
- Contacted by nurse over phone - and email - from Bournemouth before going in for tests. Emails explained things well and in a way he could understand.
- Every time he had an appointment he was sent an explanation of what was happening. He felt he could ask questions at any time.
- Had a few calls with updates - even if no new news - and had regular contact from the same nurse which he felt was very good - they knew him, and he didn't have to talk to different people all the time.
- Everyone he was in contact with was great - feels he can contact them anytime needed.
- Tests and scans were really quick - no problems at all with any of it. Very little waiting around to get in, longest wait was 45mins but that was because there were issues in the hospital - so a one off.
- Everything explained to him along the way - knew exactly what he was going in for and what to expect -
- Feels nothing could have been done better - he said "it was all brilliant" - "everything explained to me really quickly and well".
- Not sure whether he had information about lifestyle management but feels it wouldn't have been useful anyway.
- Feels very lucky to be in Dorset compared to what his friends get in other parts of the country. He hopes more people can have this kind of service in the future.

**Summary**

Good communication from the service throughout - continuity of speaking with the same person made a big difference.

## Service user ID 0004

- Quite confused - difficult to ask questions.
- Wasn't sure about why she had gone through the LNP - wasn't through a GP referral - sounds like she was already in hospital (admitted as an emergency - high temp and confused - went in twice) and was referred from there. She did say she has something wrong with the lymph gland but not sure - they said everything was OK and will monitor again in 6 months (Poole).
- She was very unsure about her diagnosis - attends hospital regularly by the sounds of it. She didn't recall having been told why she had tests - again confused - she was in Poole hospital this week (week of 2nd Feb as emergency). Was seen by GP - admitted - stayed in a few days - did tests while there - no diagnosis - says they are not sure what's the matter. Noticed lymph node issue on scan which is probably the LNP pathway - nothing to worry about - no meds - no written info provided - had someone call her to explain what was going to happen re the scan (possible LNP) - was helpful in a way but she was a bit concerned because she couldn't understand why it was happening. She wasn't sure who had phoned but thinks she may have been given a name and number but she doesn't know where it is. "It didn't register with me".
- She did feel she had the opportunity to ask questions when she was in hospital - she advised "I don't really ask questions because I feel I don't ask the right things". She gets confused and likes to take in daughter or granddaughter but "they couldn't make it this time because I'm in a lot and they can't keep taking time off so this time I took my cousin".
- She uses a buggy - doesn't drive anymore - used Attendance Allowance to get taxi as she lives fairly close to hospital. She really needs someone with her - letter about appointment said she could bring someone - no choice on appointment time but there was a number to ring if she needed to change the time.

- No problem with any treatment or experience - felt everything was done well - no problems. Thinks she did get some information about managing at home but feels she is OK.

#### Summary

Lady quite confused so it was difficult to get feedback on all the aspects. However, she had no issues or concerns about any of her treatment or care.

#### Service user ID 0005

- Was already in hospital at time of referral - had a COPD 999 call - ambulance paramedic noticed lump on side of neck - so followed up after returning home.
- Received letter referring into service - can't remember having any information apart from referral letter. Was very quick referral but can't remember how long.
- Went into Bournemouth for tests - can't remember having any phone calls from service at all - just referral letter - they did tests - they couldn't find any issues through the tests - was told at the time so didn't have to wait to get results - GP not involved at all.
- Felt he had chance to ask questions - but because he was automatically referred he didn't really have opportunity to ask (in a good way). Doesn't think anything could have been done better - appointment times were good - didn't have to wait long in waiting room for tests. No access issues.
- Everything done on same day - no further tests or follow ups - everything clear. He understood everything that was happening.

#### Summary

Again, quite difficult to elicit information. However, was happy with treatment and care and didn't think anything could have been done better.

**Service user ID 0006**

- Was referred by GP - but it was the dentist that noticed lump in throat - so went to GP and was referred.
- GP gave him some tablets first and then referred to hospital - went to Bournemouth and Poole for scans and tests. Easy to get to Bournemouth as lives locally.
- Had lots of written info from GP and hospital - very helpful - straightforward and no jargon. It was general info - (Note from AD - not sure it was about LNP specifically) - feels all the communication was very good and helpful.
- Had a few calls with KM - she explained what was going to happen about tests etc - he felt reassured. He had opportunity to ask questions, but he was “content just to let them get on with it really”.
- Discussed type of tests he was going to have - is already having chemo by the sounds of it - in fact was in hospital 4/5 hrs the day before our conversation - has low grade lymphoma. Has 3 information booklets and is “ploughing through them”.
- All appointment times have been convenient but parking for 4/5 hours can be really expensive - he did park at the hospital yesterday because he was told he was only going to be in for 2 hours but ended up being in there for 5 - so that was a “bit of a pain really in terms of expensive car parking”.
- No practical or access issues - has been given all the dates for future treatment and he’s happy with everything - can’t think of anything that could have been done better.
- He hasn’t been given any information about lifestyle/support - but he doesn’t think that would have been useful anyway. He advised “I’m in their hands, they are the professionals”.

**Summary**

Felt the calls with KM were excellent and very reassuring. Only issue was with car parking.

**Service user ID 0007**

- Went to GP with severe pain and was referred to LNP - within 12 hrs was in Bournemouth.
- GP explained what was happening and what the LNP was, but it was such a quick referral - went into Poole first - went to urgent treatment centre - scans etc - showed large mass on spine - did biopsies and then a scan - confirmed the issue - it was lymphoma - MRI in Poole - rest in Bournemouth
- No access issues with either place but Bournemouth easier - there wasn't a choice to start with though - treatment is being done in Bournemouth.
- Felt had all the information she needed - had some phone calls (note from AD - she was not sure whether these were from the LNP) - felt she could ask questions.
- There was a problem with first scan in Poole - consultant said nothing to show on scan and she would be treated for sciatica - on the way home in car, phone rang and it was a consultant apologising that there had been a mistake and told her they had found a mass on her spine - felt being told on phone like that wasn't very good - but following day she went back and saw another consultant who apologised straight away for what had happened and she shouldn't; have been told over the phone.
- Felt all the tests were done at good times and convenient - very accommodating and everything well explained.
- Had information about managing lifestyle - and some information from social care about aids in the home- she has bought some of her own - like a stairlift - is waiting to find out about attendance allowance which is taking some time. But she was told and asked about what aids would be useful. No info about local support groups/vol sector but she wouldn't have used them anyway. Has had lots of trouble getting a blue badge for car.

- Doesn't feel anything could have been better "I am full of praise for everyone involved".

#### Summary

Not sure whether communications were from the LNP. However, no issues with any of her treatment of care.

#### Service user ID 0008

- Found lump on neck - went to GP - had tablets and blood tests - didn't have effect - so GP referred him to LNP.
- Tests were done at Bournemouth. It was quite quick from referral to going in - no complaints whatsoever - everything went really well - treatment starts next week. Even over Xmas things went quick.
- Appreciates everything that's being done for him - he's had regular contact with the CNS (KM?) - "they moved heaven and earth for me".
- Feels that communication is the most important for him - "when nurse first met me she realised she would have to keep on top of comms with me!". "She was always there when I called though, and she was a good ear. I got all the info I needed and wanted. Can't fault the nurses - they are absolutely amazing. She always called at the time she said - that was very important to me".
- Feel nothing could have been done better - "anything I wasn't sure about she would email straight away or call".
- All the tests were done quickly and he didn't have to wait around for those - there were a few cancellations which may have helped and the hospital called him up straight away if there was a cancellation to see if he could get in.
- No practical issues - timings were convenient. He knows what's happening next in terms of his treatment.
- "If I have to give stars I'd give 5 out of 5"

#### Summary

Emphasised the important of clear and timely communication.

**Service user ID 0009**

- Was referred via GP. GP did not explain anything about the referral. First patient heard about it was after receiving call and follow up email from the LNP team.
- Patient unable to remember how long it was between seeing GP and receiving contact from LNP but thinks it was very quick.
- Very impressed with the communication from the service, email was clear and informative and phone call was comprehensive and patient felt he had ample opportunity to ask any questions.
- Tests were quick and went smoothly. Had to attend both Poole and Bournemouth hospitals via public transport but didn't have any issues with that.
- Test results were fast.
- LNP also gave him lots of useful information about lifestyle and other things which was very useful.
- Nothing negative about any aspect of the service or attendance for tests.

**Summary**

Couldn't think of anything that could have been done better.

Note - no service users required safety netting or further signposting.

## Limitations and Learning Points

The following limitations have been identified here (note these are not comprehensive and are based on the 9 interviews undertaken).

- Some service users were confused in terms of understanding the difference between their experiences of the LNP pathway and other treatment/pathways they may have experienced. Interviewer needed to adjust questions and prompts but some of the feedback received may relate to other services experienced.

- Service users referred to the LNP whilst already in hospital may not have received calls from the service prior to tests/scans so it was not possible to ask them about that aspect of the service.

## Conclusions

Although the original proposal was to undertake 20 service user interviews, due to a change in funding, Involving People were unable to continue with the project post July 2023.

Overall, feedback received was positive, however for some patients it was difficult for them to relate their experiences to the LNP specifically. Patients highlighted that timely and effective communication made a real difference to their experience of the service, especially when contacted by phone.

## Contact Details

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## Appendix A: Additional available documents (on request)

- a) Lymph Node Pathology Pathway Pilot: A proposed approach to public, patient, and carer involvement (Final Nov 2022)
- b) Patient Information Sheet
- c) Interview Schedules and scripts
- d) Data Protection Impact Assessment