

Opportunities and Challenges: Creating LYMPROM[®] and a National Reporting Tool

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Pain scale relating to Lymphoedema

Please indicate your pain / discomfort relating to Lymphoedema with 0 being no pain and 10 extreme pain

Heaviness scale relating to Lymphoedema

Please indicate the heaviness relating to Lymphoedema with 0 being not heavy and 10 extremely heavy

Using the scale (0 to 10) please indicate the **impact*** Lymphoedema has had on you in the past four weeks (please tick one box only for each row):

*impact is a term used to describe the extent to which Lymphoedema inhibits any aspects of your life

| | | | | | | | | | | |
|-----------------------------------|-----|--------------------------|--|--|--|--|--|--|--|--|
| Home life | | | | | | | | | | |
| Personal care | | | | | | | | | | |
| Work | N/A | <input type="checkbox"/> | | | | | | | | |
| Finances | N/A | <input type="checkbox"/> | | | | | | | | |
| Body image | | | | | | | | | | |
| Intimacy / desirability | N/A | <input type="checkbox"/> | | | | | | | | |
| Walking | | | | | | | | | | |
| Anxiety levels | | | | | | | | | | |
| Hobbies | | | | | | | | | | |
| Holidays | N/A | <input type="checkbox"/> | | | | | | | | |
| Shopping for clothes and/or shoes | | | | | | | | | | |

Please state any other parts of your life affected by Lymphoedema:

- Lymphoedema (chronic swelling) is associated with heaviness, skin changes and reduced quality of life.
- Almost 20,000 patients living with lymphoedema in Wales.
- Lymphoedema Wales Clinical Network. (LWCN) developed, validated and digitally rolled-out the lymphoedema-specific patient reported outcome measure: LYMPROM[®]
- LYMPROM[®] helps adults communicate the impact of lymphoedema by rating the impact of 13 item from 0 to 10 where 10 is extreme impact.

Method

- LWCN worked with Welsh health boards and the Welsh Value in Health Centre (WViHC) to collect LYMPROM[®] digitally.
- Paper forms were digitised in 3 Welsh health boards.
- Collected on new patient referral & follow-up care.
- LYMPROM[®] data extracted monthly from local PROM systems and submitted centrally to Digital Health and Care Wales (DHCW).
- Aggregate data reported via a Power BI dashboard and made available to NHS Wales users.

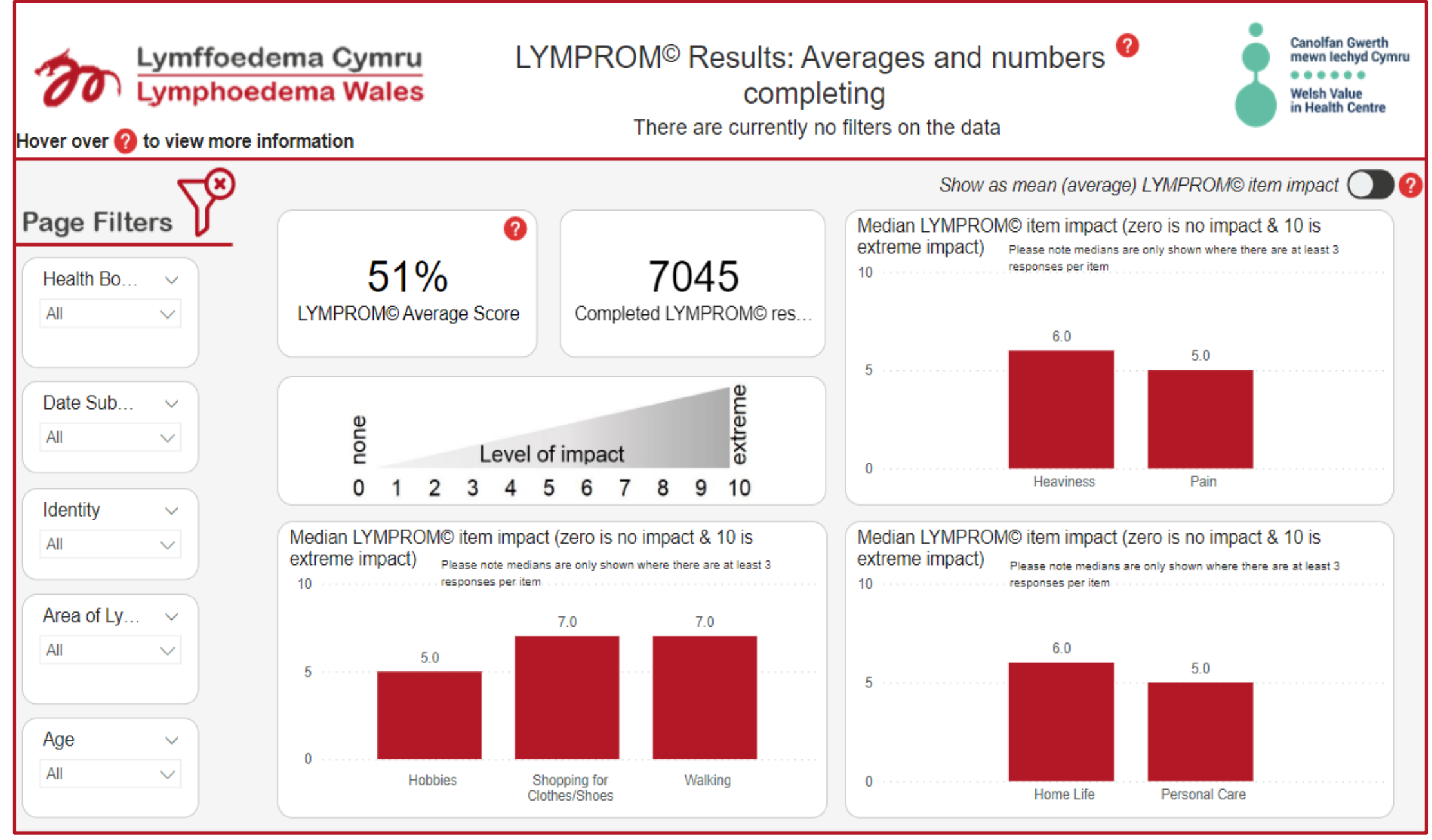
Results

- Data submission flows differed across Wales and included both manual exports and FHIR approaches
- Data provided was in varying states of maturity with unstructured and bilingual data challenges which resulted in lots of time spent data wrangling.
- Launched March 2022 with over 7,000 completions from 3 Welsh health boards.
- The biggest challenge for patients with lymphoedema is shopping for clothes/shoes (median = 7.0, IQR = 6.0) and walking (median = 7.0, IQR = 7.0).
- Visualising data using the filters suggests that challenges vary for different cohorts.

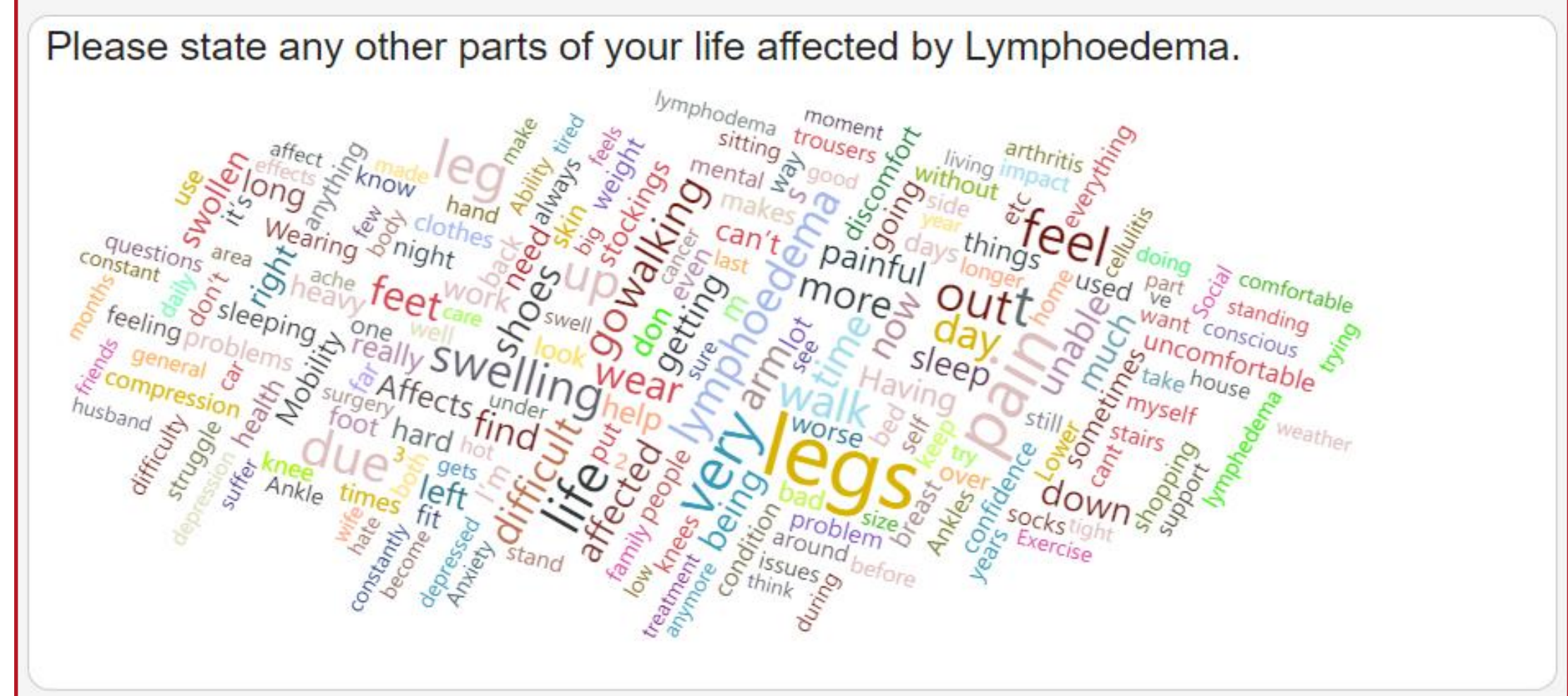
Conclusion

- A completed LYMPROM[®] prior to contact enables therapists to prioritise care and ensure the appointment is focused on what matters most to the patient.
- Collating data nationally is challenging, data flows are not always joined up.
- FHIR servers enable a more automated response for more timely data.
- Standardised data is vital to central collection.
- The national dashboard will support services to plan care and determine the effectiveness of interventions.
- Ongoing engagement & digital inclusion strategies are required.
- Ongoing work to triangulate data with routinely collected national data is required.

LYMPROM[®] 2020 Lymphoedema Wales Clinical Network (LWCN)



The LYMPROM[®] Dashboard – measuring impact



The LYMPROM[®] Dashboard – Word cloud on free text final question

