# Mobile Support Unit 2 evaluation December 2018 - August 2019



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## **Executive Summary**



This evaluation reports on data collected from 324 patients attending treatments for head and neck cancer or lymphoedema on board Tenovus Cancer Care's 2<sup>nd</sup> Mobile Support Unit between December 2018 and August 2019.

**1,650** appointments were attended at lymphoedema clinics.

**414** breast cancer patients attended lymphoedema education sessions.

**104** appointments were attended at the head and neck cancer clinic.

I was greeted with a warm smile and was given help to enter due to my disability. I find this clinic really helpful because they understand Lymphoedema and its related problems, the staff are very knowledgeable and its been a great help to me to be able to get the help that I need. "First class" service.

## **90%** of responses came from patients attending lymphoedema clinics.

**83%** of patients attended their appointment in either their own car or the car of a relative or friend.

We delivered an average of



on our second Mobile Support Unit

Satisfaction with the service was very high, with 100% participants who answered the question rating the MSU as either four or five out of five for delivering their service or treatment (97% rated it 5/5).



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#### 2 Context

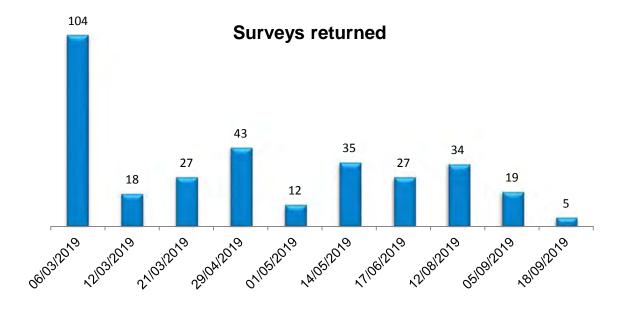
- 2.1 The four Tenovus Cancer Care (TCC) Mobile Support Units (MSUs) deliver treatments including chemotherapy, lymphoedema treatment and prehabilitation in sites across Wales and more recently, London and Surrey.
- 2.2 Our Mobile Support Units have been bringing cancer treatment and support closer to home since 2009, going to different locations each day, setting up in local car parks, supermarkets and community venues.
- 2.3 This evaluation reports on feedback received from patients in Wales on Mobile Support Unit 2 (MSU2) between December 2018 and August 2019. The majority of patients received treatment for lymphoedema.
- 2.4 Lymphoedema is a condition which can be a side-effect of cancer treatment, in particular breast cancer, which means the body's drainage system doesn't work properly. It can lead to severe swelling in the arms, legs, feet and other parts of the body which can cause mobility problems and terrible pain. It needs lifelong management.
- 2.5 There are around 10,000 people in Wales living with lymphoedema and the number is rising. It affects people physically and emotionally, and can impact every part of daily life.
- 2.6 Between December 2018 and August 2019, there were 1754 appointments on board MSU2.

	Lymphoedema clinic	Head and neck cancer clinic
Dec-18	157	11
Jan-19	217	11
Feb-19	176	11
Mar-19	200	13
Apr-19	185	13
May-19	192	18
Jun-19	153	5
Jul-19	258	6
Aug-19	112	16
Total	1650 (76%)	104 (5%)
Monthly average	183	12

- 2.1 Most appointments were for the lymphoedema clinic, in which patients with lymphoedema, either resulting from cancer or from other illnesses or injuries, are treated for their condition. Treatments include compression, specialist massage to drain the lymph system (either manually or mechanically), compression bandage changes, wound care, and measuring/fittings for compression garments. These clinics are also used to educate patients about diet and exercise, which can help reduce the severity and impacts of lymphoedema on patients.
- 2.2 The number of treatments needed by individual lymphoedema patients varies hugely, dependent on the severity of the condition. Some patients may, for example, need daily treatment to change compression bandages if their skin has split due to the condition, whilst others may only need a few treatments and be able to maintain their condition through self-massage, compression garments and exercise.
- 2.3 A further 414 patients attended lymphoedema education sessions, in which they learn about diet and exercise which can help relieve and reduce the impacts of lymphedema. These education sessions are offered postoperatively to breast cancer patients due to the increased risk of lymphoedema after mastectomy, and are delivered by Lymphoedema Wales and Breast Cancer Wales.
- 2.4 Head and neck clinics are for those affected by cancers of the head and neck (excluding the brain). These sessions allow multi-disciplinary teams comprising dieticians, nurses and speech therapists to meet with patients with head and neck cancers and deal with their specific issues.
- 2.5 Head and neck cancer patients are seen once pre-treatment (whether this is surgery, chemotherapy or radiotherapy), and usually around five times weekly post-treatment. Patients will then be seen as a minimum at six months, twelve months and twenty four months post-treatment. In some cases follow-up treatment is needed five years post-treatment.
- 2.6 MSU2 is also used for **prehabilitation sessions**, in which patients who have received a diagnosis of lung cancer engage in fitness activities designed to optimise them for surgery. This service will be evaluated separately.

### 3 Methods

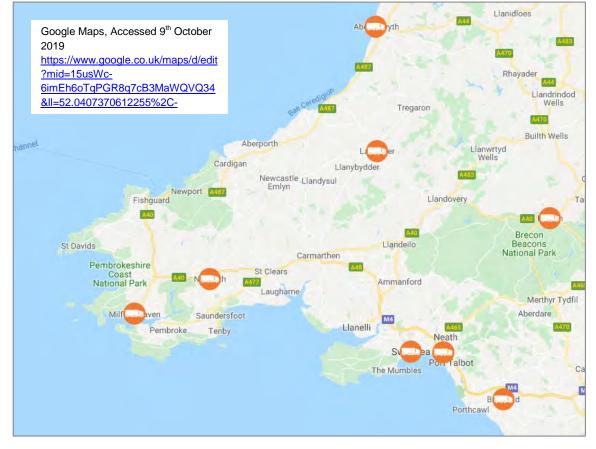
- 3.1 Surveys were distributed by the patient liaison officer to patients attending either the lymphoedema clinic or the head and neck clinic on MSU2 between December 2018 and August 2019. A few prehabilitation patients were also included in the data collection, though these were not included routinely as this service is evaluated separately.
- 3.2 Surveys were returned to head office on a fairly *ad hoc* basis, and were returned at the rate illustrated below.



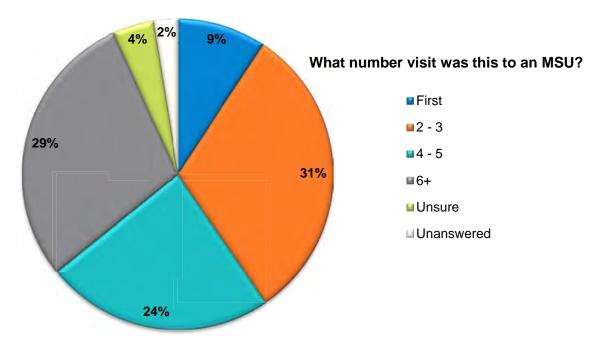
- 3.3 The survey collected data on participants experiences of the MSU, primarily focusing on the elements for which TCC are responsible or could have influence over such as the space itself and the location. If participants had comments about the medical treatment, this emerged in the 'other comments' section.
- 3.4 The survey can be viewed in full in the appendix.

## **4 Quantitative Findings**

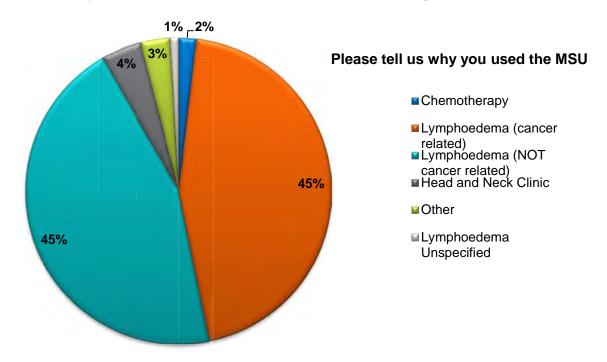
#### 4.1 We had 324 responses from 8 locations across south, west and mid Wales



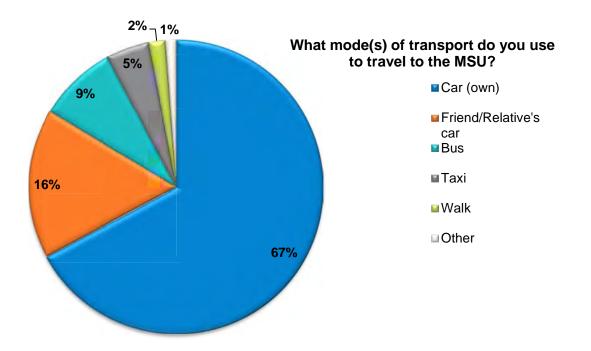
4.1 The majority of participants had visited the mobile unit before, and the survey was filled out on average on a patient's third visit to the unit.



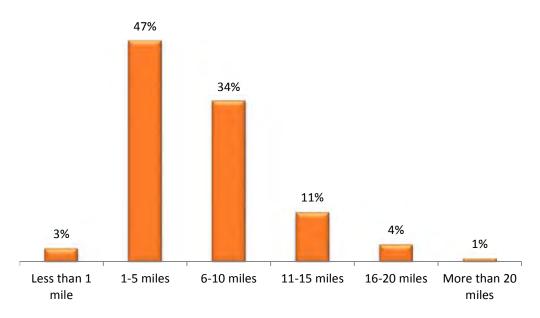
4.2 Most participants received treatment for lymphoedema, with an even split between those whose lymphoedema was or was not related to cancer. The proportion of those attending lymphoedema clinics or head and neck clinics broadly correspond to the patient numbers reported on page 3:



4.3 Two thirds of participants used their own car to travel to the unit:

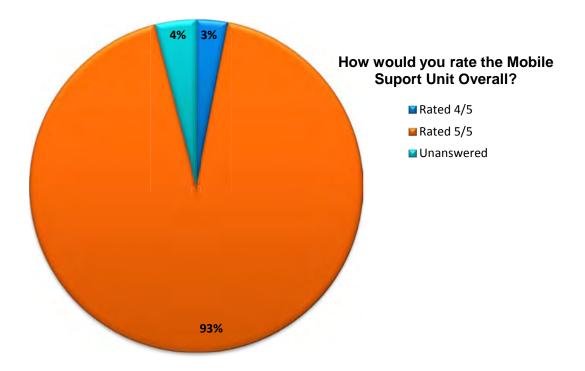


4.4 72% of respondents told us how far they travelled to reach the MSU. For these 72%, it took 17.4 minutes on average to get to the unit and participants travelled on average 6.59 miles.



If you know the approximate distance, please state it here.

4.5 Participants were asked to rate their overall experience of the mobile unit out of five. 93% of participants rated the unit five out of five.



## **5 Qualitative Findings**

- 5.1 Several questions on the survey elicited qualitative responses, and these were for the most part extremely positive. These have been grouped thematically by responses, rather than questions, due to a lot of repetition between these fields.
- 5.2 Participants were asked what their **first impression** was when they came onto the Mobile Support Unit. Only three participants (1%) had somewhat negative first impressions, and 2% of participants did not answer this question. Therefore, **97% of participants' first impressions were positive.**
- 5.3 When asked what their **most preferred part of using the Mobile Support Unit** was, 5% of participants said everything. Only 3 participants (1%) had no preferred part, and 14% did not answer.
- 5.4 When asked what their **least preferred part of using the Mobile Support Unit** was, 55% of participants said they did not have a least preferred part and 32% did not answer. The remaining 13% identified a least preferred aspect of the unit; however no aspect was particularly dominant.
- 5.5 Participants were also asked for **suggestions for improvement.** Only 7% made a suggestion, as 53% said no improvement was necessary and 40% did not answer.
- **5.6** Finally, participants were asked if they had **any other comments** about the Mobile Support Unit. 36% did not answer, 13% said they had no other comments and 2% of answers were unclear. Many participants (16%) used the opportunity to praise staff for their help, support, advice, and for being generally friendly and nice, and (22%) used the opportunity to express appreciation for the service. Some participants (8%) expressed a desire for the Mobile Support Unit to continue.

#### Positive feedback

5.7 The **members of staff in the MSU** were spoken of very positively by participants in response to the questions 'what was your first impression' and 'what was your most preferred part of using the MSU'. Members of staff were reported as helping participants feel comfortable, and reassuring them when they came onto the Mobile Support Unit and during treatment:

"Staff are wonderful and I feel valued when I come to clinic"

"I was greeted with a warm smile and was given help to enter due to my disability"

"Very friendly welcome"

5.8 The location of the Unit was mentioned very frequently, with patients grateful for the proximity to their home or work compared to their nearest hospital.

"I think in a rural area like Powys we would be lost without it."

"I feel very lucky to have such a professional, friendly service so close to home."

"Much easier than catching 3 buses to Singleton Hospital. Mobile is just around the corner from where I live, it's friendly and great people work there."

5.9 A dominant first impression among participants was **the pleasant atmosphere on board the Mobile Support Unit**. It was important to participants that they were receiving treatment in a clean, comfortable and pleasant environment:

*"[the] unit is so warm and comfortable [with] nice views to look at"* 

"Clean, organised and a relaxed atmosphere"

5.10 Several participants also commented on the **design of the unit**:

"Felt I'd entered Dr Who's Tardis - brilliant design"

"Compact and bijou"

"Light and airy and well designed."

5.11 It may also be that there is **social aspect to receiving treatment** on a Mobile Support Unit, as many participants mention how 'friendly' the atmosphere is, and that they appreciated being able to talk to the staff. Participants felt the help and advice offered by the staff was beneficial and professionally delivered:

"The help the staff gives to you and they listen, you can talk to them"

"It's great to have support, someone to talk to about any worries"

5.12 Participants preferred attending appointments on the Mobile Support Unit rather than at hospitals because it felt like a more personal experience:

*"Tend to see the same therapist so a more personal treatment experience" (Ref. 69)* 

*"I much prefer to come here than go to hospital. Here you're not [just] a number" (Ref. 64)* 

5.13 A large number of comments compared the MSU favourably to hospital visits (28 referring to unnamed hospitals and 21 referring to Singleton. 1 patient referred to Velindre).

"Every member of staff is helpful and supportive. I am very grateful to the mobile unit as Singleton seems so far away and difficult to face traveling, arranging travel, parking etc. when feeling unwell."

"So much less stressful than hospital visits."

"The mobile unit makes attendance to my appointment much easier but loses none of the quality of hospital based facilities." 5.14 A lot of participants commented on the convenience of the MSU, due to shorter distances to travel, as aforementioned, but also due to easier parking, compared to attending appointments at a hospital. Patients also commented favourably on the short distance from parking to appointment, and that they never had to wait long to be seen.

"It's much closer than travelling to Singleton and easier to park. Closer to the facilities rather than a long walk at Singleton."

"It's more convenient to get to from my home, plus parking is plentiful"

"Not long to wait, easy to get to and park"

"It's closer to home and so much easier to access than the hospital"

5.15 A few patients commented on the **communication** between the MSU staff and themselves, with 3 mentioning that the reminder call was very useful.

"I was very grateful for the phone call as a reminder of my appointment."

5.16 Below is a word-cloud generated using responses to the questions 'what was your first impression when you came onto the MSU' and 'what was your most preferred part of using the MSU?':



#### Least preferred parts of using the MSU:

- The variable or cold temperature of the unit (made by two participants; 1%);
- The steps to access the unit (made by four participants; 1%);
- The lack of privacy (made by three participants; 1%);
- Using the weighing scales (made by two participants; 1%);
- Being confused about deliveries and collection, and having to go back to collect products they needed (made by two participants; 1%);
- Having to go at all (or having to have treatment) (made by three participants;
   1%);
- Appointments only being available on certain days at certain times, and having to take time off work to attend (made by five participants; 2%).

#### Suggested improvements:

5.17 The suggestions below are divided into those over which TCC have control, those over which the NHS have control, and those which relate to the unit itself.

#### **TCC improvements**

- Arms on chairs in waiting room;
- Drinks machine for tea and coffee (made by two participants);
- Give out sweets;
- Somewhere to put clothes;
- That signs or maps were needed.

#### **NHS** staff improvements

- Deliver garments so people don't have to go back and collect;
- Support under knee to help pressure in joint;
- More frequent visits (to mid Wales) (made by two participants);
- Later appointments (made by two participants);
- Initial invitation could be more explanatory;
- Patient would like a copy of their results to compare at each visit.

#### Improvements relating to the MSU/location

- The height of the unit (patient reported being scared of lifts);
- Parking a bit difficult (Neath, patient arrived at a busy time of day (9am) and reported that there were a lot of lorries etc. moving around the site);
- Access (other comments indicate that this patient used the steps);
- A permanent building (no more unsafe feeling);
- Improved sound proofing;
- More space in private room;
- Air conditioning.

### 6 Summary and recommendations

- 6.1 The convenience of the MSU was the most commonly cited 'most preferred' element of patient experience, including the proximity to patients' home or work, the ease of parking, and the ease of getting from the parking to the unit compared to large hospital sites. Given that 83% of patients attended appointments in a car, this is an important point, supporting the continuation of this model of service delivery.
- 6.2 The friendly, professional and caring manner of the staff on board the unit is particularly important to note, and there was absolutely no negative feedback relating to this element of the patient experience.
- 6.3 Feedback from patients was largely positive; so the recommendations below are based on very small numbers of suggestions or criticisms. However, even if negative experiences are only reported by a small minority, it is important that everything is done to ensure that patients' experiences are as positive as they can be.
- 6.4 Some patients had a little difficulty finding the MSU due to varied locations. It is suggested that temporary signposts be considered to be located near the unit to help first-time visitors find the MSU. Alternatively, providing maps with appointments letters could alleviate this problem.
- 6.5 A few patients said that they had difficulty accessing the unit via the stairs. It is recommended that all patients are advised in advance of the availability of the lift to access the unit.
- 6.6 Two patients said that a cup of tea or means to make a cup of tea would have been welcome. Usually, patients are offered refreshments on arrival, but it is recommended that this is always offered to ensure that patients and visitors are well looked after while using the MSU.
- 6.7 Some patients mentioned that the unit was cold. It is recommended that fan heaters are turned on earlier or more frequently on cold days, and that the temperature on the unit be monitored.
- 6.8 Privacy seems to be an issue for a few patients. It is recommended that patients are asked if they are happy being treated without a private room, and that the curtains or the private room be used when possible if patients express this wish.
- 6.9 Many patients expressed a wish that there be increased service in their area, and more frequent or longer opening times. It is recommended that funding and logistical options be explored to increase the service provision.
- 6.10 One patient requested that sweets be provided. This is not recommended, though it could be worth informing patients with the appointment letter that patients are welcome to bring snacks with them, as some sites do not provide easy access to these.

- 6.11 Relating to the evaluation process, there is some inconsistency in how people respond to the question asking why the MSU was being visited. In future, it is suggested that this field is more specifically worded to see why they visited the unit on the day which they filled in the survey.
- 6.12 It is recommended that this survey be extended to patients receiving treatment upon MSU3 to capture more complete data of patients' experiences on our MSUs.
- 6.13 Other services provided on board the MSUs are evaluated by other organisations, including Lloyds pharmacy, the Lymphoedema service, Velindre and the Swansea UHB physiotherapy department. It is recommended that data from these organisations are also included in future reports to better understand the efficacy and levels of satisfaction with all of the services provided on TCC MSUs, both in Wales and elsewhere.
- 6.14 It is also recommended that future evaluations extend the research methods to encapsulate data from the healthcare providers working on board the mobile support units.

## **APPENDIX: Survey**

Survey October 2018



## Mobile Support Unit Evaluation Survey

We want to make sure that we are providing the best possible service, and as such we continuously evaluate the experiences of our patients.

Please fill in the following questionnaire to help us understand your experiences of the MSU.

1.	Where did	you visit the M	obile Support	Unit today?		
2.	What number visit was this to an MSU?					
	First	2-3 🗆	4-5 🗆	6+ 🗆	Unsure	

3. Please tell us why you used the Mobile Support Unit:

Chemotherapy					
Lymphoedema (car	ncer related)				
Lymphoedema (NO	T cancer related)				
Head and neck clin	ic				
Other					
If other, please spe	cify:				
	************************		***************************************		
4. What mode(s) o	f transport do you use	to travel to the	Mobile Support Unit?		
(Tick all that appl)					
Car (our)	Due	-	Train El		
Car (own)	Bus Friend / Relative's	car 🗆	Train  Other		
Taxi 🗆	Ambulance		(Please state)		
			a second sec		
5 How long on a	verage does the journ	ev to visit the M	obile Support Unit take you?		
S. How long, on a	relage, does the journ	cy to visit the lyn	ublic ouppoir officiance you:		
5 a If you know the	approximate distance	nloaco stato it	boro		
J.a. II you know the	approximate distance	, piease state it	nere		
a state of a second second	first impression when	you came onto	the Mobile Support Unit?		
<ol><li>What was your</li></ol>					
a said and a	first impression when	you came onto	the Mobile Support Unit?		

#### Survey October 2018

7. What was your most preferred part of using the Mobile Support Unit?

8. What was your least preferred part of using the Mobile Support Unit?

If you could improve anything about your MSU experience what would it be? Your suggestions will be welcomed!

10. How would you rate the Mobile Support Unit overall in delivering the treatment or service that you required?

1 🗆	2 🗆	3 🗖	4 🗆	5 🗆
Unsatisfactory				Excellent

11. Do you have any other comments about the Mobile Support Unit?

Thank you for taking part in this survey!

Evaluation helps us to ensure that our services are the best they can be, to help us to be of the most benefit to people affected by cancer, now and in the future.

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