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Title: Identifying Priorities for Physiotherapy Research in the UK: the James Lind Alliance Physiotherapy Priority Setting Partnership

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3	Priority Setting Partnership
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James Lind Alliance (JLA).

79 ABSTRACT

- 80 **Objectives:**
- To identify unanswered questions for physiotherapy research and help set and prioritise the top 10
- 82 generic research priorities for the UK physiotherapy profession; updating previous clinical condition-
- 83 specific priorities to include patient and carer perspectives, and reflect changes in physiotherapy
- 84 practice, service provision and new technologies.
- 85
- 86 Design:
- 87 The James Lind Alliance (JLA) Priority Setting Partnership (PSP) methodology was adopted, utilising
- 88 evidence review, survey and consensus methods.
- 89

90 Participants:

- 91 Anyone with experience and/or an interest in UK physiotherapy: patients, carers, members of the
- 92 public, physiotherapists, student physiotherapists, other healthcare professionals, researchers,
- 93 educators, service providers, commissioners and policy makers.
- 94

95 Results:

Five hundred and ten respondents (50% patients, carers or members of the public) identified 2152 questions (termed "uncertainties"). Sixty-five indicative questions were developed from the uncertainties using peer reviewed thematic analysis. These were ranked in a second national survey (1,020 responses (62% were complete)). The top 25 questions were reviewed in a final prioritisation workshop using an adapted nominal group technique. The top 10 research priorities focused on optimisation (top priority); access; effectiveness; patient and carer knowledge, experiences, needs and expectations; supporting patient engagement and self-management; diagnosis and prediction.

104	Conclusions:
105	This study is currently the UK's most inclusive consultation exercise to identify patients'and
106	healthcare professionals priorities for physiotherapy research. The exercise deliberately sought to
107	capture generic issues relevant to all specialisms within physiotherapy. The research priorities
108	identified a range of gaps in existing evidence to inform physiotherapy policy and practice. The
109	results will assist research commissioning bodies and inform funding decisions and strategy.
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131	Identifying Priorities for Physiotherapy Research in the UK: the James Lind Alliance Physiotherapy
132	Priority Setting Partnership
133	
134	Key messages
135	• The paper identifies ranked research priorities for physiotherapy research in the UK.
136	• Describes the James Lind Alliance's (JLA) transparent methods and process for priority setting,
137	designed to engage with key stakeholders in physiotherapy research, in particular clinicians,
138	patients, their carers and members of the public.
139	• This is one of the first attempts at profession-wide priority setting using JLA methods. It has a
140	broader scope than previous PSPs, many of which are disease-specific or treatment focused (with
141	some containing specific priorities relevant to physiotherapy).
142	• The study assists in setting the UK physiotherapy research agenda for the medium term and
143	informs funders of stakeholders' opinions, and researchers of the context and wider priorities.
144	Impact of this approach to priority setting requires evaluation
145	
146	Key Words
147	Physiotherapy, research priorities, co-production, consensus
148	
149	Purpose
150	Physiotherapy, like all healthcare professions, needs to extend and update its evidence base to
151	underpin clinical practice and demonstrate its role and value in contemporary healthcare. This
152	project aimed to identify research priorities for the UK physiotherapy profession that engage
153	research funders and researchers to develop the evidence in areas that matter most to patients,
154	carers and clinicians and that are relevant to healthcare policy. Research priorities for the
155	physiotherapy profession in the UK were last set in 2010(1) . We set out to update these priorities in

 provision and new technologies. In contrast to previous priority setting which identified speciality- and condition-specifice priorities, our approach was to analyse all suggested priorities together and investigate the feasibility of identifying priorities relevant to all areas of physiotherapy. The James Lind Alliance (JLA) is a non-profit-making initiative, bringing multiple stakeholders together in Priority Setting Partnerships (PSPs) (2). These partnerships identify and prioritise "uncertainties", or "unanswered questions", about the effects of treatments and areas of healthcare that patients, carers and clinicians agree are the most important. PSPs aim to address what has been described as the mismatch between the treatments that patients and clinicians wish to see evaluated and the treatments being evaluated by researchers (3-5). In 2017 the Chartered Society of Physiotherapy (CSP) engaged with the James Lind Alliance (JLA) to establish a Physiotherapy Priority Setting Partnership (PSP) to identify generic research priorities for the physiotherapy priority Setting Partnership (PSP) to identify and agree the most important uncertainties about and carers, funders, educators, support workers, students, service providers, commissioners and policy makers in the UK to identify and agree the most important uncertainties for physiotherapy. To agree by consensus with patients, carers and clinicians a ranked list of uncertainties for physiotherapy research, including the top ten uncertainties. To publicise the results and process of the PSP. To provide the results on research commissioning bodies in a way that helps Inform physiotherapy research strategies and funding decisions. 	156	order to include views of patients and carers, reflect changes in physiotherapy practice, service
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182 Design

183 The project was managed by a research team at the Chartered Society of Physiotherapy (CSP), the 184 professional body for physiotherapists in the UK and led by a multi-stakeholder steering group. A 185 formal report and appendices are available online (6).

186

The study was initiated with an awareness meeting in January 2017 to promote the PSP to key stakeholders, identify steering group members and partner organisations, discuss the scope of the PSP and seek advice for engaging with the community. The steering group was responsible for agreeing the initial scope of the project, publicising the PSP, overseeing the collection and analysis of the priorities, dissemination of results and taking the final priorities to research funders. A senior JLA adviser (KC) chaired the steering group, advised on methodology and facilitated the final priority-

193 setting workshop.

194

Partner organisations provided ongoing support to the PSP by promoting the project, encouraging
their members to take part in each stage and disseminating the findings. The PSP was supported by
43 partner organisations - 15 universities, 10 CSP professional networks, 8 patient groups, 5 Trusts
and commissioning groups, 4 research networks and one policy group (6: page 30).

199

The multi-stage JLA methodology 7) was used (Figure 1). In line with JLAprinciples, patients and carers were involved in the study not only as participants in the surveys and final workshop but also as members of the PSP steering group and as representatives of patient groups. Patients and carers were included in each stage of the study and engaged with decision-making, recruiting patients, reviewing and agreeing indicative questions, ranking of questions and disseminating results.

205

206 FIGURE 1 – to be inserted approximately at this location

207 Participants

8

208	As the PSP aimed to be inclusive, anyone living in the UK with an interest in physiotherapy was
209	eligible to participate in the identification of uncertainties (Stage 1, Figure 1). Examples included:
210	patients and/or carers who had experienced previous physiotherapy provision, members of the
211	public, patients, carers, clinicians, researchers, research funders, educators, students, service
212	providers, commissioners and policy makers. In line with JLA principles, only patients, carers and
213	clinicians participated in the prioritisation stages (Stages 3 and 4, Figure 1).
214	
215	Scope
216	Preliminary discussions and workshops were undertaken amongst lead CSP staff in Practice and
217	Development, Policy and relevant CSP committees in relation to the scope of the project. Early
218	feedback on the scope from the initial awareness meeting informed the Steering Group's discussions
219	on the scope. A broad scope encompassing physiotherapy for any injury, illness or disability, in any
220	setting for people of all ages was agreed with four key areas of focus - interventions, self-
221	management, prevention and service delivery
222	
223	The 4 stages are outlined below (see Figure 1):
224	
225	Stage 1
226	Literature searches to identify uncertainties
227	As part of the scoping for the project, literature searches for two policy themes identified by the
228	steering group as being relevant were undertaken (by RS) – search strategies are available in the PSP
229	online report(6: appendices 1 and 2):
230	i. Developing and sharing models of good practice for reducing the burden on secondary care.
231	ii. Promoting good practice in primary care for people with multiple morbidities.
222	

232

233 Initial Survey

234	The online questionnaire was developed in SurveyMonkey [™] and piloted by the steering group. The
235	survey was open from May to July 2017. The questionnaire (available (8)) took approximately 15
236	minutes to complete, and was also available as a paper version. Four questions in relation to the
237	areas of focus within the scope (interventions, self-management, prevention and service delivery)
238	were included:
239	1) "What question(s) do you have about physiotherapy to help people recover and get back to their
240	usual activities?
241	2) "What question(s) do you have about physiotherapy to help people manage their condition(s)
242	themselves?"
243	3) "What question(s) do you have about physiotherapy to help people to improve their health and
244	prevent disease and injury?"
245	4) "What question(s) do you have about how physiotherapy services are accessed and delivered?"
246	
247	Questions could relate to any type of physiotherapy service; for any injury, illness, condition or
248	disability; for people of any age. Demographic data was also requested.
249	
250	A website was established to advertise the partnership and the online survey. Participants were
251	recruited using convenience and purposive sampling in line with the JLA's inclusive approach (7).
252	The partner organisations, steering group members and in the CSP promoted the survey through a
253	range of advertisements to members in online and paper publications e.g. the professional magazine
254	Frontline, social media, through professional and patient networks and in clinical settings.
255	Interim demographic data about participants was provided to the Steering Committee in order to
256	identify any groups that were felt to be under-represented. Targeted strategies were used to reach
257	these groups and encourage participation.
258	
259	Stage 2

260 Data analysis and verification of uncertainties

261 Survey responses were analysed using Thematic Analysis (9); individual responses were coded with 262 similar codes being grouped together into themes. Indicative questions were created to represent 263 similarly coded responses within the themes. RS acted as primary analyst, coding the questions, 264 creating initial themes and identifying the indicative questions for review. During initial coding and 265 theme development, JW, BON, BF and AL second coded approximately a third of the data to enhance 266 consistency. GR peer reviewed all coded responses, themes and indicative questions. At regular 267 intervals, data coding, theme development and indicative questions were discussed by the steering 268 committee to refine the analysis. The steering group reviewed the indicative questions, to confirm that the final question set reflected the intent of the initial submitted questions. 269

270

Each indicative question was then checked against the existing evidence for physiotherapy. The
literature, including Ovid (Pubmed), EBSCO (CINHAL), PEDro, NICE Evidence and Cochrane databases
was searched by RS with assistance from the CSP's library and information service. A question was
considered to have been addressed if it had been included in a recent (within 5 years) systematic
review that concluded there was sufficient evidence to answer the question. Full search strategy
details are in the PSP report (6: appendix 3)

277

278 Stage 3

279 Interim Prioritisation

A second national online survey populated with the indicative questions identified from stage 2 was

open from November to December 2017. The survey was targeted to eligible participants (patients,

282 carers and clinicians) following the same strategy used to promote the initial survey. In addition,

283 participants from Stage 1 who had indicated they were willing to take part in in this stage were

contacted. Participants were invited to select and then rank their top ten questions. The questions

were presented in a random order to each participant to reduce the risk of bias.

286

287 Analysis

The results of the ranking by patients and clinicians were collated, thereby giving equal weighting toclinicians and patients, to form a ranked list of the indicative questions.

290

291 Stage 4

292 Final prioritisation workshop

293 The top 25 questions from the interim prioritisation were taken forward to a final prioritisation

workshop, a consensus meeting held London in February 2018. Thirty participants (15

295 physiotherapists, 12 patients and 3 carers) were recruited through partner organisations and

296 networks to take part. We aimed to include a diverse group in terms of their professional

297 backgrounds, experience of health conditions, age and representation across the countries in the UK.

298 A small number of steering group members and a representative from the National Institute for

299 Health Research (NIHR) attended as non-participatory observers at the workshop.

300

Participants were divided into three equal-sized groups with a mix of physiotherapists, patients and carers. The groups were asked to rank the questions using an adapted nominal group technique (10) and guided discussion facilitated by three independent JLA advisors. The rankings were collated; the groups were then mixed and asked to rank the questions a second time. The aggregate ranking from the small group exercises was then discussed by the whole group to agree the final order of questions including the top ten priorities.

307

308 Results

309 Stage 1 – Identifying uncertainties

A total of 645 responses were submitted, of which 135 did not contain questions and were excluded,

Out of the 510 included participants, 174 (34.1%) had received physiotherapy as a patient; 44 (8.6%)

312	identified themselves as carers; 36 (7.1%) members of the public with an interest in physiotherapy;
313	19 responses (3.7%) had been completed on behalf of someone else. Two hundred and thirty four
314	(45.9%) identified themselves as physiotherapists working in clinical practice (categories were not
315	mutually exclusive).
316	
317	The majority (75%) of respondents were female and the mean age was 47 years (range 9 to 88).
318	Most respondents lived across the UK (England (77%); Northern Ireland (10%); Scotland (5%); Wales
319	(4.5%); Other (3.5%). Respondents described their ethnicity as: White (91%); Asian/Asian British (1%);
320	Black/Black British (1%); Mixed/multiple ethnic groups (0.5%); Chinese or other ethnic group (0.5%)
321	or preferred not to say (4.5%).
322	For full details about respondents see the final report (6: Tables 1-4, pages 16-17)
323	
324	The 510 responses contained 2091 uncertainties. No additional uncertainties were identified from
325	the literature searches.
326	
327	Stage 2 – Analysis and Verifying uncertainties
328	The submitted uncertainties were collated and refined resulting in 2,152 uncertainties. This is
329	because when some of the uncertainties were analysed they were composed of more than one
330	uncertainty. Of these 2,152 uncertainties, 35 were considered out of scope. Following coding and
331	theming, 15 broad themes emerged. Similarly coded uncertainties were developed into indicative
332	questions producing 65 questions. The mean number of uncertainties underpinning an indicative
333	question was 33 (standard deviation (SD) 48, range 1-255).
334	
335	The secondary care search identified systematic reviews relevant for 8 of the indicative questions.
336	Fifteen additional searches were undertaken which identified systematic reviews for a further 33
337	indicative questions (6: appendix 3). All of the systematic reviews showed that uncertainty existed.

338	Therefore, 41 of the 65 indicative questions were verified as uncertainties. The remaining 24
339	questions were discussed with the steering group and considered unlikely to have relevant
340	systematic review evidence in their topics. Considering the available literature and the broad scope
341	of each of the questions, the steering group agreed that all of the indicative questions were
342	unanswered.
343	
344	Stage 3 – Interim prioritisation
345	There were 1,020 responses to the survey, 636 (62%) were complete and could be used in the
346	analyses; participant categories were not mutually exclusive: 490 (77%) identified themselves as
347	physiotherapists working in clinical practice, others as patients (n = 68 (10.7%)), carers (n = 14 (2.2%))
348	and members of the public (n = 6 (1%)).
349	
350	Respondents' mean age was 41.9 years (range 17 to 87); most described themselves as female (81%).
351	Respondents lived in England (62%); Northern Ireland (25%); Scotland (7%); Wales (3%); Other (3%)
352	and described their ethnicity as: White (94%); Asian/Asian British (1.7%); Black/Black British (0.2%);
353	Mixed/multiple ethnic groups (1.4%); Chinese or other ethnic group (0.5%) or preferred not to say
354	(2.5%). For full details (6: Table 5 page 19, appendix 4)
355	
356	Ranking of questions
357	The separate rankings from the patient/carer and clinician groups were weighted equally and
358	combined to form a ranked list of the top 25 uncertainties to take forward to the workshop in Stage
359	4. For the combined list of the 25 priorities taken forward, as well as the ranked list from the patient
360	and clinician groups, see the Physiotherapy PSP final report (6: Table 6 page 20).
361	

362 Stage 4 – Final prioritisation

14

363	The final top ten priorities (see Table 1 below) fall within six themes: optimisation of physiotherapy
364	(top ranked question, underpinned by 18 uncertainties); access (three questions); effectiveness
365	(three questions); patient and carer knowledge, experiences, needs and expectations; supporting
366	patient engagement and self-management; diagnosis and prediction. The number of uncertainties
367	underpinning each of the top ten questions ranged from 3 – 255.
368	
369	Table 1 – to be inserted approximately at this location
370	
371	Discussion
372	Our study identified a ranked list of uncertainties relating to physiotherapy in the UK that includes
373	the top ten research questions. These uncertainties reflect the ambitious aim of the project to
374	develop priorities for a profession which covers diverse specialisms delivered in multiple settings and
375	potentially serves all groups in society across the life course. In addition, they address the key
376	elements within the scope of interventions, self-management, prevention and service delivery and
377	are relevant for contemporary healthcare and policy in the UK. The themes of the top 3 priorities are
378	optimisation, effectiveness and access.
379	
380	With patients, carers and members of the public forming half of the participants in the initial survey
381	and equal weighting being given to them in the priority setting compared to clinicians, the
382	methodology we used allowed patients and the public to contribute to setting the physiotherapy
383	research agenda. The process was carefully monitored and overseen by the steering group
384	consisting of multiple diverse stakeholders with a range of expertise and the independent JLA. The
385	new priorities reflect moves to improve impact by wider stakeholder engagement, attempts to
386	embed collaborative patient engagement in the coproduction of research ((11, 12) and a shift in
387	thinking away from expert-led research agendas (13).
388	

389	The well-established JLA methodology and philosophy add strength to the resulting top 10. A recent
390	systematic rapid review considered this type of methodology to be "robust, strategic and aimed to
391	promote equity in patient voices" (14).

392

393 Our approach to identifying broad generic priorities differs from the speciality- and condition-394 focused approach of the previous UK physiotherapy priority setting project (1). A significant strength 395 of this approach was the removal of potential bias from overrepresentation of participants with a 396 specific condition or area of expertise. It also allowed participants to fully engage with all of the 397 priorities. The priorities not only focus on physiotherapy interventions but how services are 398 delivered, self-management and prevention. Importantly, the priorities can be widely adapted and 399 adopted by researchers and interpreted by research commissioners. Another advantage is that 400 generic priorities are less fixed and prescriptive, allowing for the inclusion of new technologies or 401 innovations.

402

Further work needs to be undertaken by researchers with relevant stakeholders to develop the priorities into specific research questions. They can be interpreted alongside other condition- and speciality-specific priorities and research recommendations. However, it is also important that researchers address the urgent need for evidence about physiotherapy for people with multiple physical and mental health conditions. Impact of this approach to setting the profession's research priorities requires evaluation in terms of influencing research funding and uptake and development of the priorities by researchers.

410

411 Previous JLA PSP's have typically been single condition- or issue-focused, many including

412 recommendations for research into physiotherapy related to specific conditions, for example, stroke,

413 multiple sclerosis, scoliosis and urinary incontinence (15). More recently, the scope of some PSPs has

414 broadened to include a wide range of conditions (for example, 'multiple conditions in later life'), as

415	well as care settings (for example, 'intensive care') (16). The physiotherapy PSP was the first
416	profession specific PSP. Recently, an adult social work PSP has identified their top 10 priorities and
417	an occupational therapy PSP is underway (15).
418	
419	The traditional purpose of JLA PSPs is to identify uncertainties about treatment effects. It is apparent
420	from the scope and emerging priorities of more recent PSPs, for example, the palliative and end of
421	life care PSP (15), that, how treatment and care are delivered is also important to patients, carers
422	and clinicians. Expanding the scope of PSPs to encompass service delivery also identifies
423	uncertainties relevant to healthcare policy. The JLA regularly reviews its principles and methodology.
424	The physiotherapy PSP has the broadest scope to date and the methods we used to address the
425	associated challenges is informing discussions about developing JLA approaches (2).
426	
427	A limitation of this study is the low response from across the physiotherapy profession (with CSP
428	membership of approximately 57000) despite wide publicity. The exception to this is Northern Irish
429	respondents who demonstrated relatively high levels of engagement. The sampling method used in
430	the last CSP priority setting exercise (1) was fundamentally different to the approach used in the
431	current project and therefore we have no comparative data in relation to our response rate. Further
432	work is needed to understand factors affecting physiotherapists' engagement with research priority
433	setting. However, appropriate representation from all key stakeholder and demographic groups is
434	probably of more relevance than response rate in this type of large population study.
435	
433	

437 second survey although this would have been attenuated by the equal weighting given to the

- 438 clinician and patient groups in the aggregated ranking. Participants in the workshop were selected
- 439 with a view to gaining broad representation, within the constraints of feasibility and resources.
- 440

441 As a whole the participants predominantly described themselves as White; with males, members of 442 Black, Asian and minority ethnic (BAME) groups and those in young and old age groups being under-443 represented. The questionnaire was available in a variety of formats to try to improve accessibility 444 e.g. paper-based, Welsh language, but the impact of these on response rates is unclear and may not 445 have accommodated the communication needs of all potential participants e.g. those with visual 446 impairment or without English as their first language. Responses could be made by proxy, and a small 447 number of participants took this option. Targeted strategies used to engage with networks for older 448 and younger participants and BAME groups had limited success.

449

450 Underrepresentation of BAME groups is a recognised limitation of many of the JLA PSPs (2). Effective 451 strategies have been suggested by the Type 2 Diabetes PSP (16). Previous disease-specific PSPs have 452 had some success with enhanced models of engagement with people with complex health needs ("assisted involvement")(17). Further work on identifying and evaluating methodologies to improve 453 454 engagement and participation among professional groups and populations which are labelled "hard-455 to-reach" (18,19,20) should be considered. Limited feasibility and resource limitations have been 456 identified as challenges to engagement with all relevant stakeholders (14) and are likely to have played a part in our study. Some models of engagement may be more feasible in PSPs with a 457 458 narrower scope.

- 459
- 460

461 Observers in the final workshop noted the subtle realignment of priorities during discussions in each 462 group session which progressively led to agreement on the final ranking of the priorities. This is a key 463 component of the JLA methodology that might be further researched to better understand and 464 potentially enhance the steps in the consensus building process.

465

466 Conclusion

18

467	This study provides an opportunity for patients and carers, as well as clinicians and other
468	stakeholders, to influence and guide the physiotherapy profession's research agenda in the UK. A
469	focussed approach was used to agree the top ten physiotherapy research priorities out of 65
470	identified uncertainties. Using the JLA's established methods provided a unique perspective on the
471	wide scope of physiotherapy practice in the UK and co-produced a prioritised list of generic research
472	themes that encompass clinical practice, self-management, prevention and service delivery. These
473	are flexible and can be further refined to produce specific research questions that are highly relevant
474	to clinicians and patients. It is important that the impact of this approach to priority setting is
475	evaluated.
476	
477	Implications
478	The results will directly inform, guide and influence physiotherapy research funding, commissioning
479	and decisions to produce evidence that matters to clinicians and patients. Other professional groups
480	may be interested in our methodological approach to priority setting across a wide scope of practice.
481	Common challenges around maximising engagement and representation of professional groups,
482	patients and public should be tackled in future research.
483	Word count approx. 3,500
484	
485	Conflict of Interest: The authors disclose no conflicts of interest.
486	
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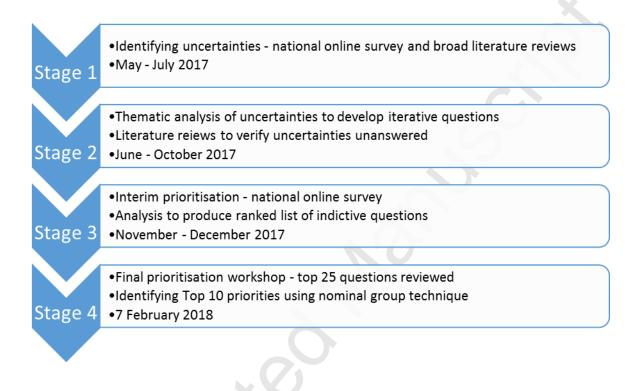
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559		

FIGURE 1

Overview of the 4 key stages of the James Lind Alliance methodology as applied to the

Physiotherapy Priority Setting Partnership



Rank	Priorities	Theme	Number of uncertainties
1	When health problems are developing, at what point is physiotherapy most/least effective for improving patient results compared to no physiotherapy? <i>What</i> <i>factors affect this</i> ?	Optimisation	18
2	When used by physiotherapists, what methods are effective in helping patients to make health changes, engage with treatment, check their progress, or manage their health after discharge?	Effectiveness	190
3	What are the best ways to deliver physiotherapy services to meet patients' needs and improve outcomes for patients and services?	Access	255
4	To stop health problems occurring or worsening, what physiotherapy treatments, advice or approaches are safe and effective? Where more than one treatment/approach works, which work best and in what dose?	Effectiveness	34
5	What are patients' expectations regarding recovery, how do these compare to physiotherapists' views and, where recovery is not possible, how is this managed?	Patient & Carer knowledge, experiences, needs and expectations	15
6	How does waiting for physiotherapy affect patient and service outcomes?	Access	17
7	What parts of physiotherapy treatments cause behaviour change or physical improvement?	Effectiveness	3
8	What approaches are effective for enabling parents, relations or carers to support physiotherapy treatment or to help patients to manage their own health problem?	Supporting patient engagement and self- management	24
9	How is patient progress and/or the results of physiotherapy treatment measured? <i>How is service performance measured and checked?</i>	Diagnosis and prediction	11
10	How can access to physiotherapy be improved for groups who have reduced access?	Access	22

Table 1 Physiotherapy priorities – Top ten priorities after final workshop