# **BMJ Open** What follow-up interventions, programmes and pathways exist for minor stroke survivors after discharge from the acute setting? A scoping review

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### ABSTRACT

**Objective** To identify the breadth and range of follow-up interventions currently provided to people after minor stroke with a focus on the definitions used for minor stroke, intervention components, intervention theory and outcomes used. These findings will inform the development and feasibility testing of a pathway of care. **Design** Scoping review.

**Search strategy** The final search was run in January 2022. Five databases were searched—EMBASE, MEDLINE, CINAHL, British Nursing Index and PsycINFO. Grey literature was also searched. Title and abstract screening and full-text reviews were conducted by two researchers and a third was involved when differences of opinion existed. A bespoke data extraction template was created, refined and then completed. The Template for Intervention Description and Replication (TIDieR) checklist was used to describe interventions.

**Results** Twenty-five studies, using a range of research methodologies were included in the review. A range of definitions were used for minor stroke. Interventions focused largely on secondary prevention and management of increased risk of further stroke. Fewer focused on the management of hidden impairments experienced after minor stroke. Limited family involvement was reported and collaboration between secondary and primary care was seldom described. The intervention components, content, duration and delivery were varied as were the outcome measures used.

**Conclusion** There is an increasing volume of research exploring how best to provide follow-up care to people after minor stroke. Personalised, holistic and theoryinformed interdisciplinary follow-up is needed that balances education and support needs with adjustment to life after stroke.

Every year, >150 000 people in the UK experience a stroke and a quarter of stroke survivors are under the age of 65 years.<sup>1</sup> The social and economic impacts of stroke in the UK are vast with an annual societal cost of approximately £26 billion.<sup>2</sup> Furthermore, the incidence and prevalence of stroke are both projected to increase over the next two decades.<sup>3</sup>

### STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The study's methodological strengths are that a protocol was published and that a recognised framework and guidance were used alongside reporting guidelines.
- ⇒ Another strength is that findings were enhanced by involvement of service users in shaping the question and providing insights into the findings.
- ⇒ The lack of consensus on the definition of minor stroke and our decision to exclude studies where the majority of participants had a diagnosis of transient ischaemic attack could be viewed as a limitation. It is possible that some studies with the population of interest were missed because of this. Introduction

Improving stroke care is a priority area in the NHS Long-Term Plan<sup>4</sup> and life after stroke is emphasised in the Stroke Action Plan for Europe 2018–2030.<sup>5</sup> Improving the stroke pathway, reducing the risk of further stroke and managing hidden impairments experienced after stroke have all been identified as priority research areas.<sup>6</sup>

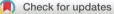
Prevalence studies have identified that a third<sup>7</sup> to half<sup>8</sup> of the stroke population experience a so-called 'minor stroke'. This scoping review focuses on services for this group of people who are assumed, often incorrectly, to have made a full recovery. Confusingly, there is no clear consensus on the definition of minor stroke.<sup>9–11</sup> What is known is that after minor stroke people face an increased risk of recurrent, potentially more severe stroke.<sup>12</sup> <sup>13</sup> They also experience hidden impairments, including cognitive problems,<sup>14–17</sup> low mood,<sup>18–20</sup> anxiety<sup>21</sup> and fatigue<sup>22 23</sup> and these impact on their ability to fulfil previously valued activities and roles as well as negatively impacting their quality of life and sense of well-being.<sup>24–28</sup>

The reality for people and their families after minor stroke is that subtle hidden impairments,

**To cite:** Crow J, Savage M, Gardner L, *et al.* What followup interventions, programmes and pathways exist for minor stroke survivors after discharge from the acute setting? A scoping review. *BMJ Open* 2023;**13**:e070323. doi:10.1136/ bmjopen-2022-070323

Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/ bmjopen-2022-070323).

Received 18 November 2022 Accepted 15 May 2023



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Correspondence to Mrs Jennifer Crow; jcrow@ic.ac.uk not apparent in hospital, manifest after discharge when people attempt to resume their prestroke lives. A recent study found that 9 out of 10 participants reported stroke-related problems at 3months after discharge.<sup>29</sup> Problems relating to hidden impairments, secondary prevention and life after stroke were commonly reported and participants under 65 years presented with more problems than those over 65 years. Alongside this, stroke survivors and their families report feeling abandoned and struggle to access support when back in the community.<sup>12 24 30 31</sup>

A working group of people with transient ischaemic attack (TIA), minor stroke and other key stakeholders agreed by consensus that their top research priority was identifying the most effective follow-up pathway.<sup>32</sup> An early scoping review (search November 2015 to January 2016) published on this topic found 12 relevant studies<sup>33</sup> and a more recent scoping review focused specifically on psychoeducational interventions for people after TIA or minor stroke.<sup>34</sup> The original review concluded that more research focusing on the development and evaluation of services supporting the transition from the acute setting to the community is needed. The second review found that both the definitions used for TIA and minor stroke and the interventions delivered were poorly described.

Given the rapid increase in research publications in this area and the specific focus of the recent scoping review by Kontou *et al*,<sup>34</sup> it was felt that a new overview of all follow-up provided was justified. Within this review, our definition of follow-up refers to interventions, other than routine medical follow-up, delivered once the person with minor stroke has left hospital. It does not include interventions delivered in hospital nor early supported discharge or community stroke therapy services provided to those with obvious physical, cognitive or psychological impairments. The focus of this review is on those with a diagnosis of minor stroke who are currently considered 'too good' for existing stroke services. The main objective of this scoping review is to identify the breadth and range of follow-up interventions currently provided to people after minor stroke, and questions will focus on:

- 1. The definitions used for minor stroke.
- 2. The components of the interventions delivered.
- 3. The behavioural or psychological theories used to inform the intervention development.
- 4. The outcomes reported.

### **METHODS**

The scoping review was undertaken using the six-step framework developed by Arksey and O'Malley.<sup>35</sup> As proposed by Levac *et al*<sup>36</sup> and endorsed by Colquhoun *et al*,<sup>37</sup> the optional sixth stage was included to add methodological rigour. The scoping review methodology does not seek to answer efficacy questions but rather to map the literature available on the topic, identify key concepts and their components, theories and gaps in the research.<sup>38</sup> Formal assessment of methodological quality is not recommended.<sup>39</sup> The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) scoping review checklist was used to guide the reporting and ensure that the preferred reporting standards, transparency and accuracy were met (online supplemental file 4).<sup>40</sup> The review protocol was registered with the Open Science Foundation and can be found at https://doi.org/10.17605/OSF. IO/9FE3C.

### Patient and public involvement

A patient and public involvement (PPI) group informed the review question and provided insight into the findings during the review process. An acute stakeholder group (stroke consultant, stroke specialist nurse, stroke therapists and stroke management), two primary care practitioners and a primary care researcher contributed their perspectives. Their input highlighted the tension between secondary and primary care regarding where the responsibility of delivering a follow-up service should lie and the challenges of providing stroke specialist input throughout the recovery and adjustment phase. The PPI group expressed a dislike for the term 'minor stroke' as they felt this minimised the event and implied that the impact on their lives was inconsequential. Their perspectives added lived experience, content expertise and perspective to the findings.

### Data sources and search strategy

The search strategy was developed and piloted by the review team with support from a senior healthcare librarian (LG). Initial searches were conducted in EMBASE, MEDLINE and CINAHL. Keywords in the titles and abstracts of relevant articles were noted, Medical Subject Headings terms were reviewed, and ongoing refinements were made until agreement was reached on the final terms of the search strategy. The search strategy was published with the registered protocol and can be found in online supplemental file 1.

In September–October 2020, the following databases were searched-EMBASE, MEDLINE, CINAHL, British Nursing Index, PsycINFO. Grey literature repositories-OpenGrey, Google, Trip and Stroke Association reports were also searched. No restrictions were placed on years. Only articles written in English were included because of resource limitations. Hand searching was conducted through reviewing the reference lists of relevant articles. In cases where only the abstract could be found, at least two attempts were made to contact the authors to explore whether the work had been published. Due to disruptions caused by the pandemic, work was paused for a year. For this reason, the literature search described was repeated in January 2022 using the same search strategy and same databases, date limits were applied such that only articles published between November 2020 and January 2022 were considered. This revealed a further three studies that met the inclusion criteria.41-43

### **Eligibility criteria**

The following inclusion criteria were applied:

1. At least half of the study population had minor strokes (modified Rankin Score (mRS) ≤2) and had been admitted to hospital.

- 2. The intervention had a behavioural component delivered individually or in a group and commenced within 3 months of discharge.
- 3. Studies had to include at least one of the following outcomes of interest: stroke knowledge, cognition, mood, medication adherence, fatigue, physical activity measures, lifestyle changes, quality of life, activities of daily living, participation, self-efficacy, self-management, economic evaluations.
- 4. All study types were included.

Studies were excluded if the population was >50% moderate or major stroke or TIA. Existing community therapy services tend to focus on those with obvious impairments following their stroke, and clinical services are often not commissioned to provide follow-up beyond secondary prevention for people after TIA. Solely pharmacological interventions and studies that reported only cardiovascular scores, biomedical markers or hospital readmission outcomes were excluded.

### **Procedure**

All references were imported into Covidence (https://app.covidence.org/sign\_in) and duplicates were removed. All titles and abstracts were screened by JC and then either MS, CH or CC. Any disagreements were resolved by a third review team member and consensus was reached regarding inclusion or exclusion of the study for full-text review. This process was repeated for the full-text reviews.

### **Data extraction and charting**

A bespoke data charting form was created by the review team. Charting should be an iterative process<sup>36</sup> and three researchers trialled charting five studies before categories were: study details (title, authors, year of publication), geographical location, study design, stated population, minor stroke definition, number of participants, research question, inclusion and exclusion criteria, description of the intervention (how, where, what, when, by whom), theory, primary and secondary outcome measures, results and economic evaluation. Alongside the data charting form, the TIDieR checklist<sup>44</sup> was completed for each intervention to enable a consistent review of each intervention's reported components online supplemental file 2.

### RESULTS

The initial search retrieved 7524 studies. Title and abstract screening were conducted using the review inclusion and exclusion criteria and this number was reduced to 77 full-text articles. Following the full-text review, 27 research papers were included; 25 original studies and 2 studies with more than one relevant publication for inclusion.<sup>45 46</sup> See figure 1 for the PRISMA flow diagram. A summary of the included studies can be seen in table 1.

### Study design, participant characteristics and inclusion/ exclusion criteria

A range of different study designs were used: single-centre pilot randomised controlled trials (RCTs),<sup>42 47</sup> pilot non-randomised studies,<sup>48 49</sup> feasibility studies,<sup>50 51</sup> mixed methods,<sup>52</sup> pragmatic cluster randomised trial,<sup>53</sup> proof-of-concept validation study,<sup>43</sup> prospective cohort trials<sup>51 54</sup> and multicentre RCTs.<sup>55 56</sup>

The number of participants in the studies ranged from 8<sup>43</sup> to 6024 in the Comprehensive Post-Acute Stroke Services (COMPASS) study.<sup>53</sup> The total number of participants in the included studies is 12525. Three large recent studies contributed 10 271 to this total.<sup>53 55 56</sup> The included studies were all conducted in middle-income to high-income countries: Israel (2), the USA (4), Hong Kong (1), New Zealand (2), Japan (1), Canada (3), the UK (2), Norway (2), Denmark (1), Austria (1), Germany (1), Sweden (1), Switzerland (1), Italy (1), The Netherlands (2).

A number of studies did not specifically mention minor stroke, but on examining the participant characteristics it was clear that the included population experienced minor strokes (discharge modified Rankin Score (mRS)  $\leq$ 2). In some studies, the aetiology of the stroke determined inclusion, for example, the presence of modifiable cardiovascular risk factors<sup>54 55</sup> or non-cardioembolic strokes.<sup>57</sup> In other studies, haemorrhagic strokes were excluded.<sup>47 51 54 58</sup> In the cardiac rehabilitation interventions, those with unstable cardiac conditions were excluded.<sup>49 50 59</sup> Cognitive impairment was an exclusion criteria for many of the studies, although the specific measure used was not always explicitly stated and the cut-off points varied.<sup>47 49 60</sup> Some studies excluded people with 'dementia'<sup>42 50 61 62</sup> and others specified 'significant/ severe dementia'<sup>57 59</sup> as an exclusion criteria.

### **Minor stroke definitions**

The terminology used and definitions provided for minor stroke varied considerably: they included minor ischaemic stroke, TIA, minor stroke, non-disabling stroke, stroke, mild stroke, mild non-disabling stroke, first ever stroke and stroke with minor residual deficits. Where definitions were provided for the participant population, there was no universally agreed definition. Operational definitions included discharge mRS (<2,  $\leq 2$ ,  $\leq 3$ ), admission NIHSS and discharge Barthel Index score.

### **Intervention details**

There were 25 different follow-up interventions, details of each are captured in the TIDieR checklist. The rationale provided for the specific interventions delivered could be divided into two main groups: (i) education and exercise interventions that focused on secondary prevention and managing increased risk of further stroke and (ii) education and support interventions that touched on hidden impairments and other impacts of stroke. The outlier, e-health solution for home patient telemonitoring,

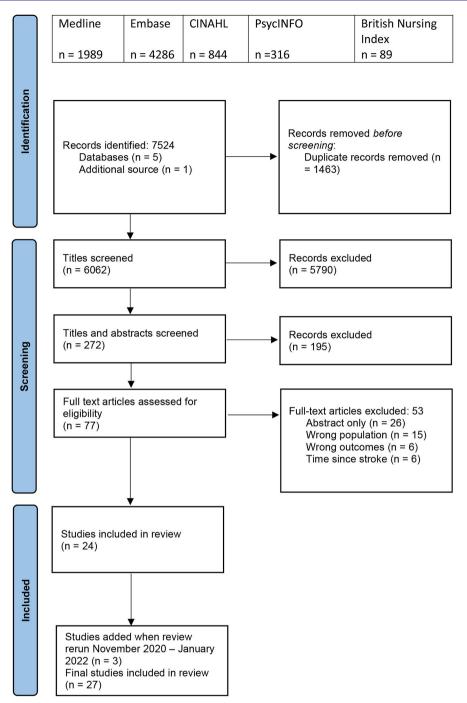


Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram.

developed in response to the COVID-19 pandemic, focused on early discharge from the acute setting.  $^{\rm 43}$ 

The interventions were delivered by a range of professionals including specialist stroke nurses, cardiac rehabilitation staff, physiotherapists, occupational therapists, stroke physicians and neurologists. A handful of studies described an interdisciplinary and holistic approach from initial assessment with personalised care plans being developed and referrals made onto appropriate specialists as needed.<sup>53 63-65</sup> Delivery was usually in an outpatient clinic setting, although three studies involved visiting participants in their own homes.<sup>61 64 66</sup> Some interventions required specialist training for delivery.<sup>47 55 66 67</sup> Ten interventions were group-based, eight involved cardiac rehabilitation groups and the other two focused exclusively on education, goal setting, self-management and behaviour change.<sup>47 58</sup> Four interventions were delivered by telephone only,<sup>62 68–70</sup> one by SMS<sup>42</sup> and one a combination of virtual monitoring and telephone.<sup>43</sup> The commencement of the intervention ranged from 2 days<sup>53</sup> to 3 months postdischarge.<sup>56</sup>

The duration, intensity and dose of the intervention was also variable. This ranged from fairly intensive exercise and education programmes running more than once

Table 1 Included studies	dies			
Author, location,	Study Design, Participant number	Participant characteristics I=intervention, C=control	Study aims	Primary outcome
Adie and James, <sup>62</sup> UK	RCT 56	Minor Stroke (MS) 57%, TIA 43% Median mRS 2 (IQR 2)	Does telephone follow-up improve risk factor management in hypertensive patients after stroke and TIA?	No significant difference in SBP over 6 months.
Ahmadi <i>et al,<sup>55</sup></i> Germany, Denmark	RCT 2098	I: MS 62.6%, TIA 37.4% C: MS 61%, TIA 39%	Does a support programme for enhanced secondary prevention reduce the frequency of recurrent vascular events?	No significantly lower rate of major vascular events after 3.6 years. Improvement in some secondary prevention targets.
Ajčević <i>et al</i> , <sup>43</sup> Italy,	Proof of concept validation study 8	MS 5, TIA 3 NIHSS: 0-2, mRS: 0-1	To design, implement and test an e-health telemonitoring system to support patients with MS/TIA in the early postacute phase.	Prompt identification of vital sign alterations possible, allowing necessary interventions. Improvement in QOL, reduced anxiety and depression.
Allen <i>et al</i> , <sup>64</sup> USA	RCT 96	NIHSS: I: 2.1 (0.4), C: 1.9 (0.4)	To measure effectiveness of a comprehensive interdisciplinary postdischarge stroke care management model.	Improvements in their profile for health and stroke prevention seen. Most improvement in stroke knowledge.
Arts <i>et al</i> , <sup>48</sup> The Netherlands	Pilot study, no control, mixed methods 42	TIA 36%, MS 60%, other 4%	To measure: (i) feasibility, (ii) satisfaction with the programme, (iii) factors associated with satisfaction.	71% satisfied with outpatient care. Satisfied patients had increased ADL independence. Dissatisfied patients more depressed and QOL lower.
Brouwer-Goossensen <i>et al</i> , <sup>41</sup> The Netherlands	RCT phase II trial 136	I: MS 69%, NIHSS 1 (0–1) C: MS 68%, NIHSS 0 (0–2)	To evaluate the effectiveness of MI to encourage lifestyle behaviour changes after TIA or minor ischaemic stroke.	Results do not support MI in supporting lifestyle behaviour change, although overall lifestyle behaviour change was high in both groups.
Clague-Baker <i>et al</i> , <sup>s2</sup> UK	Mixed methods, feasibility study 32	NIHSS 2 (IQR 1-3)	To determine feasibility outcomes; recruitment, acceptability to patients and staff, adherence, adverse events and acceptability of outcome measures	Definitive study is feasible. Recruitment rate 3/month, qual data provided insight into why patients declined. Adherence good. Outcome measures, majority able to do ISWT.
Duncan <i>et al,</i> <sup>53</sup> USA	Pragmatic cluster randomised trial 6024	l: stroke 58.1%, NIHSS 1 (0–3) C: stroke 57.3%, NIHSS 1 (0–3)	To develop and test a comprehensive postacute stroke transitional care management programme.	SIS-16 no clinically relevant effects on functional outcomes or mortality Self-reported BP monitoring more in intervention arm.
Faulkner <i>et al,</i> <sup>59</sup> New Zealand	Randomised, parallel- group, clinical trial 55	TIA or mild, non-disabling stroke as determined by a specialist stroke physician	To assess the effect of an exercise and education programme, implemented soon after stroke on psychosocial health outcomes.	Early engagement in programme may lead to some perceived psychosocial benefits in health and well-being. These may be maintained for 12 months.
Faulkner <i>et al,</i> <sup>45</sup> New Zealand	Randomised, parallel- group, clinical trial 55	TIA or mild, non-disabling stroke (determined by specialist stroke physician)	To screen hospital records of programme participants at 3.5 years after intervention to follow-up clinical outcomes and cost implications.	Fewer recurrent stroke/TIA, patient deaths and hospital admissions. Hospital costs were significantly lower for the intervention group.
				Continued

### Open acc<u>ess</u>

Table 1 Continued				
Author, location,	Study Design, Participant number	Participant characteristics I=intervention, C=control	Study aims	Primary outcome
Fu <i>et al</i> , <sup>66</sup> New Zealand	RCT 400	C: 73% mRS ≤2, I: group 1: 81.8% mRS ≤2, I: group 2: 76.1% mRS ≤2	To determine if 'take charge' improves HRQOL, 12 months poststroke and if a second session is more effective than one.	Improved HRQOL, 6 months after stroke, sustained at 12 months. Two sessions better than a single session.
Gilham and Endacott, <sup>70</sup> UK	Single blind, RCT 52	Independent, competent adults able to influence their health behaviour	To measure readiness to change health- related behaviour.	No difference between groups for readiness to change behaviour, although a clinically significant effect in reported exercise and diet in intervention group.
Green <i>et al</i> , <sup>60</sup> Canada	RCT 200	l: mRS 0 74%, mRS 1–2 23% C: mRS 0 75% mRS 1–2 25%	To examine the impact of intervention on acquisition of stroke knowledge and influence on lifestyle behaviour changes.	Improvement in stroke knowledge seen and a significant shift from a passive to active stage of change in intervention group.
Ihle-Hansen, <sup>46</sup> Norway	Ihle-Hansen, <sup>46</sup> Norway Evaluator blinded, RCT I: stroke 70%, 195 (0–1) C: stroke 77% (0–2)	I: stroke 70%, TIA 24%, mRS 1 (0–1) C: stroke 77%, TIA 12%, mRS 1.3 (0–2)	To investigate structured and multidisciplinary follow-up+intensive vascular risk management on anxiety and depression 1-year poststroke.	Programme may be associated with reduced HADS scores and lower prevalence of depression 1 year poststroke.
Ihle-Hansen <i>et al</i> , <sup>65</sup> Norway	Evaluator blinded, RCT I: stroke 70%, (0–1) C: stroke 77% (0–2)	I: stroke 70%, TIA 24%, mRS 1 (0–1) C: stroke 77%, TIA 12%, mRS 1.3 (0–2)	To investigate impact on the incidence of cognitive symptoms 1 year after stroke in patients without prestroke cognitive decline.	The programme did not reduce the incidence of cognitive problems 1 year after stroke.
Kamm <i>et al,</i> <sup>51</sup> Switzerland	Prospective, interventional cohort study 105	Stroke with minor or no residual deficits 81.1%, TIA 18.9%	To evaluate feasibility and effectiveness of a comprehensive outpatient rehab programme with secondary prevention and neurorehabilitation.	The programme is feasible and effective to improve vascular risk factors, neurological function and HRQOL.
Kono <i>et al,<sup>57</sup></i> Japan	RCT 70	mRS 0-1 I: NIHSS 2, C: NIHSS 2	To determine if a lifestyle intervention can reduce stroke recurrence or new vascular events.	Lifestyle intervention with appropriate medication is beneficial in reducing the incidence of new vascular events and improves vascular risk factors.
Prior e <i>t al,</i> <sup>54</sup> Canada	Prospective cohort trial 100	MS 50.5%, TIA 49.5%	Is CCR independently associated with improved anxiety, depression, QOL and cognition?	Anxiety and depression persisted, promising for secondary prevention, CCR was not independently associated with psychological improvements.
Rochette <i>et al</i> , <sup>68</sup> Canada	Single blind, multi- centre RCT 186	Mild stroke (mRS 0–2)	To determine if a multimodal support intervention impacts unplanned use of health services and improved QOL.	No significant group differences found on unplanned use of health services or QOL.
Sides <i>et al</i> , <sup>69</sup> USA	Two-arm pilot study 30 I: NIHSS 2 (1– 10.5% C: NIHSS 1 (1- 20%	I: NIHSS 2 (1–4), MS 89.5%, TIA 10.5% C: NIHSS 1 (1–2) MS 70%, TIA 20%	To assess (i) feasibility and (ii) impact on medication knowledge and appointment keeping.	Study demonstrated feasibility of intervention with a trained coach, small possible trend towards improved appointment keeping.
				Continued

Table 1 Continued				
Author, location,	Study Design, Participant number	Participant characteristics l=intervention, C=control	Study aims	Primary outcome
Sit <i>et al</i> , <sup>58</sup> Hong Kong Quasi-experimental study 190	Quasi-experimental study 190	MS or TIA	To determine the effectiveness of a community-based stroke prevention programme.	Study found a 3-month sustained effect of positive change in knowledge and skills.
Steen Krawcyk <i>et al</i> , <sup>61</sup> RCT 71 Denmark	RCT 71	I: SSS 54.6 (±5.8) C: SSS 55.3 (±4.4)	To determine feasibility and effect of early, HIIT is feasible and safe but did not yield home-based HIIT.	HIIT is feasible and safe but did not yield effect on cardiorespiratory fitness.
Tanne <i>et al,</i> ª Israel	Pilot, non-randomised trial 52	Pilot, non-randomised Minor ischaemic stroke (mRS ≤2) trial 52	To assess the tolerability, safety and effect The programme is feasible, well tolerated of outpatient supervised exercise training. and associated with improvement in exercise capacity.	The programme is feasible, well tolerated and associated with improvement in exercise capacity.
Toledano-Zarhi <i>et al</i> , <sup>50</sup> Pilot RCT 28 Israel	Pilot RCT 28	l: mRS 0 7%, 1 43%, 2 50% C: mRS 0 36%, 1 50%, 2 14%	To examine the feasibility, safety and effectiveness of an early aerobic rehabilitation programme.	Programme is feasible and well tolerated and associated with improved walking endurance.
Vahlberg <i>et al,</i> <sup>42</sup> Sweden	RCT 79	I: MS 72.5%, TIA 17.5%, ICH 10% C: MS 71.8%, TIA 15.4%, ICH 12.8%	TIA 17.5%, ICH 10% To evaluate whether daily mobile phone 5, TIA 15.4%, ICH messages with training instructions over 3 months increases physical activity and overall mobility.	Three months daily mobile phone messages with guided training instructions improved walking performance and lower body strength.
Willeit <i>et al</i> , <sup>56</sup> Austria	Pragmatic, open-label, two centre RCT 2149	Pragmatic, open-label, 1: NIHSS 3 (1–6), mRS 1 (0–2) two centre RCT 2149 C: NIHSS 3 (1–6), mRS 2 (0–2)	To determine if the disease management programme can prevent cardiovascular disease and improve QOL.	Programme reduced cardiovascular risk and improved HRQOL and functional outcome.
Wolf <i>et al</i> , <sup>47</sup> USA	Exploratory RCT 71	Mild stroke (NIHSS <6)	To evaluate the feasibility and preliminary effect of the chronic disease self- management programme.	No positive effect seen to support the use of the CDSMP with people post mild stroke.
BP, blood pressure; CCR, incremental shuffle walk t	, comprehensive cardiac reh test; MI, motivational intervie	BP, blood pressure; CCR, comprehensive cardiac rehabilitation; HADS, Hospital Anxiety and D noremental shuffle walk test; MI, motivational interviewing; mRS, modified Rankin Score; MS,	BP, blood pressure; CCR, comprehensive cardiac rehabilitation; HADS, Hospital Anxiety and Depression Score; HIIT, high-intensity interval training; HRQOL, health-related quality of life; ISWT, incremental shuffle walk test; MI, motivational interviewing; mRS, modified Rankin Score; MS, minor stroke; NIHSS, National Institutes of Health Stroke Scale; RCT, randomised controlled trial; CCD and the stroke scale and the stroke scale and the stroke scale and the stroke scale interviewing; mRS, modified Rankin Score; MS, minor stroke; NIHSS, National Institutes of Health Stroke Scale; RCT, randomised controlled trial; CCD and the stroke scale and the stroke s	ning; HRQOL, health-related quality of life; ISWT, th Stroke Scale; RCT, randomised controlled trial;

SBP, systolic blood pressure; SSS, Scandinavian Stroke Scale; TIA, transient ischaemic attack.

weekly for 6–24 weeks poststroke<sup>51 54 57 59</sup> to less intensive interventions such as a one-off comprehensive multidisciplinary follow-up clinic.<sup>56</sup> Telephone support ranged from follow-up at 2 and 6weeks only<sup>70</sup> to 12 follow-up calls over a 6-month period.<sup>68</sup> The longest total intervention duration was a multicomponent support programme incorporating motivational interviewing, this involved eight face-to-face appointments and continued up to 24 months poststroke.<sup>55</sup> Brief interventions included 15 min motivational interviewing sessions by an experienced nurse practitioner at 4, 8 and 12 weeks<sup>41</sup> and daily mobile phone messages for 3 months.<sup>42</sup> The e-health intervention provided constant monitoring for 14 days.<sup>43</sup>

Most of the interventions required low-tech and lowcost materials such as home-exercise booklets, printed care plans, educational materials, physical activity diaries and pedometers. However, one study provided participants with stationary bicycles for use at home<sup>61</sup> and the e-health solution required a tablet plus portable devices for vital signs monitoring and a panic button. Online information resources were used as an adjunct to provide education in the STROKECARD study.<sup>56</sup>

Intervention components not routinely described included family involvement, liaison with primary care, education and support for hidden impairments and onward referrals to appropriate specialists. Eleven of the studies mentioned supporting self-management.<sup>41 47 53 55 56 58-60 62 66 70</sup> One study included carers in its outcome measures<sup>66</sup> and no fidelity testing was described. All intervention components are presented in online supplemental file 3.

Economic analysis or comment on the economic context was seldom mentioned. Two studies considered the economic context in terms of reimbursement for intervention delivery.<sup>51 53</sup> A comprehensive postacute stroke transitional care management programme, using no additional personnel resources,<sup>53</sup> found their intervention was not easily implemented into real-world clinical practice. Another study looked at hospital admission costs at 3.5 years after the programme.<sup>45</sup> Fu *et al* estimated and reported on the direct cost of delivering their intervention.<sup>66</sup>

### **Behavioural or psychological theories**

Four different psychological theories were described in five studies to underpin the intervention development and delivery. They were (i) health belief model for behaviour change,<sup>59</sup> (ii) transtheoretical model of change,<sup>60 70</sup> (iii) self-determination theory<sup>66</sup> and (iv) social cognitive theory.<sup>62</sup> Motivational interviewing as a technique to support behavioural change was mentioned in six studies.<sup>41 55 60 62 70</sup>

### **Outcomes**

The large range of different outcome measures used are presented in table 2. The WHO International Classification of Functioning was used as a framework to structure this table.<sup>71</sup> The time point at which outcome measures

were recorded ranged from immediately postintervention<sup>50 51 54</sup> to  $3 months^{53 70}$  and 12 months after the intervention.<sup>56 59 65 66</sup> Two studies looked at recurrent rate of vascular events and this was measured after 3 years.<sup>45 55</sup> An education and exercise lifestyle intervention delivered over 24 weeks, measured recurrent vascular events at 2.9 years.<sup>57</sup>)

### DISCUSSION

This scoping review reveals a growing number of studies focusing on follow-up care after stroke and alongside this, large-scale initiatives such as the NHS Long-Term Plan<sup>4</sup> and Stroke Action Plan for Europe<sup>5</sup> support the importance of improving life after stroke. The variations in intervention content and delivery, however, highlight the different targets for the intervention and the many unanswered questions that exist. There are clear challenges inherent in developing an intervention that is sufficiently personalised to meet the varying needs of this heterogeneous population. This complexity is further exacerbated because these interventions are delivered at a time of transition when care is being handed from secondary to primary care. These interventions are complex and multicomponent and therefore this discussion will use the updated framework for the development and evaluation of complex interventions to further explore the findings.<sup>72</sup>

Firstly, stakeholder involvement is key: meaningful engagement with both those receiving the service and those delivering it is crucial. Without this the intervention is unlikely to meet service user needs and unlikely to achieve meaningful changes to policy and practice. The unmet needs of people after minor stroke have been described but less has been published on their perceptions of follow-up programmes such as those included in this review. One mixed methods feasibility study included a description of participant feedback.<sup>52</sup> Engaging with the workforce delivering these interventions is also critical given clinical pressures and resource implications. Collaboration with other professionals within the multidisciplinary team as well as developing nursing and other advanced practitioner roles could support implementation of holistic follow-up interventions. This review provided a few examples of information being shared between secondary and primary care<sup>55 65 69</sup> but despite the importance of this transition of care there was almost no description of true collaboration between services.

Secondly, identifying the multiple uncertainties that exist helps to frame the research question and research perspective. The lack of a universally agreed definition for minor stroke continues to create challenges at the bench and the bedside. From a research perspective, inclusion criteria remain variable in minor stroke studies, and in studies targeting all people after stroke, participants are in some instances largely minor stroke.<sup>42 46 56</sup> From the perspective of the person with minor stroke, eligibility for and access to ongoing services depend on

	WHO International Classification of Functioning	ning			
	Doddi firmation (Churchtern)		Participation		Time
orugies	Boay Iunction/Structure	Activity measures	measures	Uther measures	point
Adie and James <sup>62</sup>	∆SBP*,	Self-reported exercise, healthcare contacts, smoking, medication knowledge	EQ-5D, mRS		6 months
Ahmadi <i>et al<sup>55</sup></i>	Composite of major CVD* events BP, LDL, BMI	Self-reported physical activity, stair climbing, medication adherence, smoking			3 years
Ajčević <i>et al</i> <sup>43</sup>	Achievement of risk factor targets, HADS*	Adherence to medical therapy, TUQ*	EQ-5D-5L		3 months
Allen <i>et al</i> <sup>64</sup>	Profile of health and prevention NIHSS*, complications, BP, depression, management of risk, CES-D	BI*, stroke knowledge	SA-SIP30*		3 months
Arts et al <sup>48</sup>	HADS	BI	mRS*, SF-36*	Satisfaction with stroke care	6 months
Brouwer- Goossensen <i>et al<sup>41</sup></i>	Weight, BP, cholesterol, blood glucose, waist circumference	waist Predefined lifestyle behaviour change measure		Change in self-efficacy, intention to change lifestyle behaviour	6 months
Clague-Baker <i>et al</i> <sup>52</sup>	BP, HR, weight, BMI, NIHSS, fatigue, HADS, tone, physical activity, fatigue (MFIS)	ISWT*, falls, SAKQ*	SF-36	Feasibility outcomes, AE*, qualitative interviews, focus groups	6 weeks
Duncan <i>et al<sup>53</sup></i>	PHQ-2, MOCA, mortality, BP, fatigue	Medication adherence, falls	Stroke Impact Scale-16, mRS	PROMIS, self-rated healthcare satisfaction	90 days
Faulkner <i>et al</i> <sup>45 59</sup>	HADS, profile of mood states, <b>recurrent</b> stroke or TIA, mortality, hospital admissions	IPAQ*, Stanford Medical Centre Stroke Awareness Questionnaire	SF-36 component scores (2015)	SF-36 component Hospital admission costs scores (2015) (2017)	8 weeks, 12 months, 3.5 years
Fu <i>et al</i> <sup>66</sup>	Recurrent stroke, mortality	Frenchay Activities Index, BI, carer strain index,	<b>SF-36 Physical,</b> EQ VAS, mRS	Delivery cost	6, 12 months
Gilham and Endacott <sup>70</sup>	HADS	Exercise frequency, alcohol, smoking, fruit and vegetable consumption		Readiness to change health behaviour	3 months
Green <i>et al</i> <sup>60</sup>	HADS	Stroke knowledge		Stage of change	3 months
Ihle-Hansen <i>et al</i> <sup>46 65</sup>	<b>TMTA</b> , 10-word test, diagnosis of dementia or mild cognitive impairment, HADS				12 months
Kamm <i>et al<sup>61</sup></i>	Impact on vascular risk factors–BP, HR, LDL, VO2 max, BMI, HADS	9-hole peg test, 6MWT, one leg stand	HRQOL*, SF-12		3 months
Kono et al <sup>57</sup>	Stroke, cardiac death, hospitalisation for CVD*, BP, HDL, LDL, HbA1c, CRP, weight, BMI				6 months, 2.9 years
					Continued

Table 2 Continued					
	WHO International Classification of Functioning	ning			
Studies	Body function/Structure	Activity measures	Participation measures	Other measures	Time point
Prior <i>et al</i> <sup>54</sup>	HADS, TMTA, RAVLT*, Digit-symbol, TMTB, Clock Drawing, oral verbal fluency, MMSE		SF-12		. <sup>*</sup>
Rochette <i>et al<sup>68</sup></i>	Beck Depression Inventory II		Euroqol-5D, QOL index, LIFE-H*	Unplanned use of health services, planned use of health services	6 months, 1 year
Sides <i>et al</i> <sup>69</sup>	Rehospitalisation, ED visit, PHQ-8	Medication persistence knowledge, appointment keeping,	EQ-5D, mRS	Feasibility outcomes, feedback on coaching script	3 months
Sit et a/ <sup>58</sup>		Stroke knowledge, self-health monitoring, diet, exercise, smoking, medication adherence			1, 3 weeks
Steen Krawcyk <i>et</i> al <sup>61</sup>	<b>Cardiorespiratory fitness,</b> MFI*, depression, MOCA, endothelial function, BP, blood markers, BM	Physical activity	WHO-5		3 months
Tanne <i>et al</i> <sup>49</sup>		<b>6MWT, Modified Bruce Test</b> , 10MWT, TUG, functional reach			*- -
Toledano-Zarhi <i>et</i> a/ <sup>50</sup>	BP, HR	6MWT, stairs timed, FSST*		Feasibility – adherence, safety	3 months
Vahlberg <i>et al</i> <sup>42</sup>		<b>6MWT, chair stand test</b> , 10MWT, short physical performance battery			3 months
Willeit <i>et al</i> <sup>56</sup>	Composite CVD* (non-fatal or vascular death), vascular target levels, behavioural and treatment targets		<b>EQ-5D-3L</b> , mRS		12 months
Wolf et al <sup>47</sup>		Healthcare utilisation	WHO-QOL questionnaire	CDSES*, adapted illness intrusiveness ratings	P-I*, 6 months
*Key provides full name of measures. +	e of measures.				
AE, adverse events; B <sup>I</sup> protein; CVD, cardiova lipoprotein; HR, heart r	A. Adverse events; BMI, body mass index; BP, blood pressure; CDSES, Chronic Disease Self-Efficacy Scale; CES-D, Centre for epidemiological studies depression scale; CRP, C reactive protein; CVD, cardiovascular disease; ED, emergency department; FSST, four square step test; HADS, Hospital Anxiety and Depression Score; HbA1c, hemoglobin A1c; HDL, high-density lipoprotein; HR, heart rate; HRQOL, health-related quality of life; IPAQ, International Physical Activity Questionnaire; ISWT, incremental shuffle walk test; LDL, low-density lipoprotein; LIFE-H,	onic Disease Self-Efficacy Scale; CES-D, Centre r square step test; HADS, Hospital Anxiety and D ational Physical Activity Questionnaire; ISWT, inc	for epidemiological stu Depression Score; HbA1 sremental shuffle walk te	dies depression scale; CRP, C r c, hemoglobin A1c; HDL, high- st; LDL, low-density lipoprotein	active density ; LIFE-H,

walking test; 10MWT, 10 m walk test; PHQ-8, eight-item Patient Health Questionnaire; P-I, postintervention; RAVLT, Rey Auditory Verbal Learning Test; SAKQ, Stroke Attitude and Knowledge Questionnaire; SA-SIP30, stroke adapted, 30 item sickness impact profile; SA-SIP30, Stroke adapted 30 item sickness impact profile; SBP, systolic blood pressure; SF-12, 12-item Short Form; SF-36, 36-item Short Form; TUQ, Technology Usability Questionnaire; VAS, Visual Analogue Scale. inpoproterity my, my, mean rate, mword, mean related quarry or me, mov, international ringore work the struct downers in poproterity inpoproterity incrementation as the struct downers in poproterity internation as sees and the habits; MCI, mild cognitive impairment; MFI, multidimensional fatigue inventory; MFIS, multidimensional fatigue inventory score; mRS, modified Rankin Scale; 6MWT, 6 min or life; IPAQ, International Physical quality JUCL, nealtnпрорготелт; пт, пеат гате; пт

local interpretations of minor stroke. There is also uncertainty regarding what the key components of the intervention should be; secondary prevention and education are currently prioritised over the hidden impacts experienced and adjustment to life after stroke. Nine of the papers listed in online supplemental file 3 referred to hidden impacts<sup>46 65 66</sup> but input varied from a 1 hour lecture on psychological coping strategies,<sup>51</sup> to screening and onward referrals to psychology and relevant community therapies.<sup>53 56 64 68</sup> Accessing psychological support after stroke is a number one research priority<sup>6</sup> and yet psychology involvement and onward referrals were lacking in many of the interventions reviewed. Cognitive impairment after minor stroke is widely reported<sup>15–17 73 74</sup> and yet only one intervention, delivered by an occupational therapist and neuropsychologist, had poststroke cognition as its focus.<sup>48</sup> Exclusion of participants with cognitive impairment limits the generalisability of findings to real-life settings. Mental and physical fatigue after stroke received limited attention in the follow-up interventions reviewed and yet fatigue can significantly impact quality of life, return to work and social roles.<sup>73 75 76</sup> There was also no specific mention of return to work which is surprising given the impact this has on the person with stroke, their family and the associated societal economic impact.

A further two core elements described in the complex intervention development framework are developing and refining programme theory and, alongside this, refining the intervention. These elements are based on using evidence and theory to clarify the key components of an intervention, how they work together and the conditions needed to support them. Although four psychological theories were mentioned, none reported on their mechanism of action or the specific behavioural change techniques that were being targeted.<sup>59 60 62 66 70</sup> Motivational interviewing was used, mostly in connection with secondary prevention and behaviour change  $^{41\,55\,60\,62}$ rather than as a strategy to support navigating life after a minor stroke. None of the studies reviewed provided explanation of a programme theory and the proposed mechanisms of action.

The final two core elements are the context in which the intervention is being developed and economic considerations. A person's social context can potentially thwart or enhance their recovery and adjustment to life after stroke. Despite this, there was little description of family or carer involvement in the interventions. Given the integral role of family in recovery and adjustment to life after stroke, this is an important component of any intervention. Consideration of the sociopolitical and economic context was limited in the interventions reviewed. Leveraging existing services such as cardiac rehabilitation services for those with vascular risk factors represents one approach to this issue. Health economic evaluations are crucial if research is hoping to influence policy change and clinical practice.

Finally, the remit of a scoping review is not to comment on efficacy of interventions, but our methodology enabled exploration of the intervention components used and those missing. The new NIHR/MRC guidance for complex intervention framework<sup>72</sup> could support future intervention development, implementation and review. It is ideally placed to accommodate the complexities of the heterogenous stroke population, their varied contexts, the complexity and range of their needs and the real health inequalities faced by people with stroke.

There are a number of implications for clinical practice from this review. There needs to be enhanced focus on family involvement in follow-up interventions. Clinicians targeting behavioural change need to understand the underpinning theory and have training in the behavioural change techniques they are using in practice. Clinicians and service providers need to consider what training and skill sets are required to provide holistic follow-up. A focus on improving communication between secondary and primary care is crucial as both are critical in risk reduction and early adjustment to life after minor stroke.

A limitation of this scoping review relates to the inconsistent terminology and definitions used for 'minor stroke'. We attempted to be as thorough as possible in the search terms we used but it is possible that our search strategy could have inadvertently resulted in some relevant studies being missed.<sup>77-79</sup> Studies included were based on authors' local definitions of TIA and minor stroke, which could lead to inconsistencies in the included studies. The search terms used aimed to focus the search on follow-up provided to people after minor stroke but in so doing we may have compromised the breadth of the search by missing relevant studies targeted at all people with stroke. The focus on postdischarge interventions also meant that interventions commenced in the acute setting and continued in the community were not eligible.<sup>80</sup> Another limitation was that we only included studies printed in English. We did not identify any grey literature that met our inclusion criteria but have referred to relevant policy relating to the review question.

Future studies in this area may benefit from utilisation of the new NIHR and MRC Framework for Complex Intervention<sup>72</sup> development. This would assist in accommodating the multicomponent nature of the interventions, the diverse characteristics of the recipients and the contexts in which they are implemented. Inclusion criteria for future interventions need to be pragmatic and inclusive and reflect the real-life stroke population. Interventions would be enhanced by the use of appropriate theory that aims to support self-management, behaviour change and adaptation to life after stroke.

### CONCLUSION

This review has revealed that follow-up care for people after minor stroke tends to focus largely on secondary prevention and less on the hidden impairments and adjustment to life after stroke. There is scope to develop more personalised and holistic follow-up interventions

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that are underpinned by theory and focus on bringing together disparate systems. Consultation with stakeholders is crucial to understand the context of both service users and service providers and consideration of the wider determinants of health will be essential in service redesign. Encouragingly, UK policy and practice is increasingly focusing on improving long-term care for people after stroke and on working in integrated ways across the care pathway. The development of new interventions, pathways and programmes need to be underpinned by the Stroke Association's vision that people have fewer strokes and that those who are affected by stroke are supported to get the help they need to 'live the best life they can'.

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Acknowledgements The authors thank the patient public involvement group who have provided the lived experience knowledge, guidance and support with development and interpretation of findings in this scoping review. The authors also thank Ed Walshe for supporting with data analysis.

**Contributors** JC was responsible for all major areas of concept development, study planning and manuscript writing. LG, MS and CH supported with development of the research terms and initial searching. MS, CH and CC were involved in article selection and data extraction. MS, LG and CC provided manuscripts edits. PM and MW provided oversight and manuscript edits. JC is the author acting as guarantor.

**Funding** JC, HEE/NIHR-Stroke Association Pre-Doctoral Clinical Academic Fellowship, NIHR 300359 was funded in partnership by Health Education England (HEE), NIHR and Stroke Association, this award ended January 2022. Since September 2022, JC, Clinical Doctoral Research Fellow (NIHR302124) is funded by HEE/NIHR for this research project.

**Disclaimer** The views expressed in this publication are those of the author(s) and not necessarily those of the NIHR, HEE, Stroke Association, NHS or the UK Department of Health and Social Care.

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the 'Methods' section for further details.

### Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement All data relevant to the study are included in the article or uploaded as supplementary information. All data relevant to the study are included in the article or uploaded as online supplemental information. No additional data available.

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