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Abstract

This systematic review of literature evaluates evidence about effective and inclusive care management strategies for learners with type 1 diabetes in UK primary schools. Approximately 29,000 children in the UK are currently living with special health care needs of type 1 diabetes (Juvenile Diabetes Research Foundation, 2021a), and governing policies indicate an inconsistent approach to learner care, highlighting the need for improved school services. Findings included clear identification of key stakeholder roles, collaborative working, provision of adequate school staff training, enabling student self-management, and delivery of individual healthcare plans.

Keywords: type 1 diabetes, student self-management, individual health care plan, special healthcare needs, chronic conditions

Meeting the Needs of Learners with Type 1 Diabetes in UK Primary Schools: A Systematic Literature Review of Comparative Practices

Per the Equality Act 2010, type 1 diabetes is considered an unseen disability within the United Kingdom (UK; UK Government, 2010). Approximately 29,000 children in the UK are living with type 1 diabetes (Juvenile Diabetes Research Foundation [JDRF], 2021a). This high prevalence chronic condition drives the need for inclusive, effective diabetic care in primary schools. Several globally renowned statutory documents, including the United Nations Convention on the Rights of the Child (United Nations Children's Emergency Fund [UNICEF], 1989), The Salamanca Statement and Framework for Action on Special Education Needs (UNESCO, 1994) and The United Nations Convention on the Rights of Persons with Disabilities (UN, 2006), combine as drivers to ensure equitable and inclusive education for learners with special health care needs.

Type 1 diabetes "is the result of an auto-immune process, where the insulin-producing B cells of the pancreas are destroyed" (Telford, 2017, pp. 713-714). Long-term treatment through constant blood-sugar monitoring and insulin administration combined with a healthy diet and exercise regimen is paramount for managing diabetes. This treatment can be challenging and involves effective self and team management (Krone et al., 2009). The worldwide incidence of type 1 diabetes in children is increasing approximately 4% annually. Europe holds the highest prevalence, with just over 160,000 cases of juvenile type 1 diabetes (International Diabetes Federation [IDF], 2019), far surpassing North America, which holds the second highest ranking with an estimated 120,000 cases. Narrowing the scope to a national level emphasizes the high juvenile incidence in the UK and situates a systemic examination. In 2019, the UK ranked 6th internationally on cases of type 1 diabetes in children; however, the number of cases is increasing faster than other regions, seeing an estimated 3,500 new cases annually (ibid). Increasing prevalence of type 1 diabetes in children and the educational detriment of poor control emphasizes the need for school staff to be adequately prepared to support learners. It encourages reflection upon school-based practices and legislation governing provision. Ensuring effective diabetes management is a collaborative effort of many stakeholders, often involving the child and their caregiver, General Practitioner, Diabetes Specialist Nurse, practice nurse, endocrinologist, dietician, podiatrist, ophthalmologist, and possibly a child psychologist. As primary school-aged children spend significant portions of their time at school, school staff must be suitably trained and actively involved in inclusive diabetic care. Primary school staff need to understand the complexities of the condition and have specific knowledge of characteristics and treatment of hyperglycemia and hypoglycemia. It is also vital that practitioners are aware of the potential impact this condition can have on the learner's experience of school, particularly their performance, participation, and enjoyment.

Poorly controlled diabetes can result in cognitive deficits (Brands et al., 2005). Reported implications include slower information processing, attention deficits, memory impairments, and a reduced problem-solving capacity (Hershey et al., 1999). Both hypoglycaemic and hyperglycaemic episodes lead to a decline in cognitive skills, an awareness educators need of how type 1 diabetes can adversely impact a child's learning. Research shows the long-term benefits of tightly controlled diabetes, with early control resulting in fewer diabetes-related health problems (The Diabetes Control and Complications Trial Research Group [DCCT], 1993). Strict glucose monitoring following diagnosis lowered the risk of diabetic eye disease by 76%, diabetic kidney disease by 50%, and diabetic nerve disease by 60% (DCCT, 1993). Schools are responsible for the health and safety of all children; therefore, schools should consider their role in ensuring appropriate diabetic care as well as how the efficacy of their care affects learners' overall health. Effective school-based care could profoundly benefit learners with diabetes, both academically and physiologically.

Setting the Context and Conceptual Framework

Individuals with type 1 diabetes have complete insulin deficiency, which results in abnormal and elevated blood glucose levels (Kengne, 2012). Subcutaneous insulin delivery is required to regulate levels (Atkinson, 2014); if insulin is not administered or is incorrectly dosed, the individual can be at risk for diabetic ketoacidosis and long-term complications (Papatheodorou et al., 2017). Regular glucose monitoring is required to inform dosage and treatment. Therefore, it is vital that all members of the school management team are trained and aware of the care plan for a child's welfare and to avoid acute complications.

In response to the increasingly complex needs of young children with chronic conditions, teachers are continually working to employ inclusive practice (Macartney, 2012). Bronfenbrenner's Ecological Model (1975) relates key factors, concepts, and variables regarding inclusive, school-based diabetic care foundational to this review. As a conceptual framework (Maxwell, 2005), the Ecological Model acknowledges the complexity of managing a health condition in childhood, the modern-day classroom, and a promise of inclusion. It also provides a structure for understanding interactions of a multi-agency approach to school-based diabetic care across the UK. This development theory provides an interlocking overview of how individuals interact with and are influenced by their environment (1979). The health and care of the learner is impacted through relationships with family, peers, and school staff (Microsystem), interactions and relationships between parents, school, and healthcare providers (Mesosystem), parent's schedules and parental perceptions and understanding of diabetes medication, technology, and research (Exosystem) and diabetes policies and governing legislation (Macrosystem). All interactions are influenced by technological advances and personal diabetes requirements over time (Chronosystem). Therefore, a breakdown in relationships between stakeholders and changes in policy could have a devastating collateral effect on aspects of care.

Nations of the UK, that is England, Scotland, Wales, and Northern Ireland, present separate legislation and educational policies which guide the care of learners with medical conditions. Within the Education Act 2010, all schools within Britain are held responsible for providing "reasonable adjustments" to ensure children with diabetes and other disabilities are not educationally disadvantaged (UK Government, 2010). Beyond this, schools are expected to train staff and create a whole-school medical conditions policy, yet statutory guidelines are variable and vague regarding what schools and teachers must do. Table 1 provides an overview of variable legislation in UK jurisdictions. Different approaches are exemplified through Scotland's national Getting it right for every child (GIRFEC) framework, which adopts a holistic approach to learner wellbeing (Scottish Government, 2006). GIRFEC is a strengths-based approach aiming to uphold the rights of every child, and in accordance with this vision, practitioners must provide all children and their families with the *right support* at the *right time* (ibid). Are learners with type 1 diabetes receiving effective school-based care? What is effective in supporting learner well-being and holistic development? Legislation and policies are continuously evolving to answer these questions, but there is yet to be consistent legislation and guidance for learners with chronic health conditions across the UK.

Teachers are voicing concerns and reservations when caring for learners with type 1 diabetes. An international collaborative study titled the *Diabetes Attitudes, Wishes and Needs* (DAWN) project set out to improve the overall healthcare systems of people with diabetes in every country (Lange et al., 2009). The DAWN study highlighted diabetic management in schools as a key area of concern. A study conducted in Germany highlighted that teachers feel insecure when providing diabetic care, particularly when administrating insulin (Gutzweiler et al., 2020). School management plans were also shown as ineffective, and

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guidelines for practice lacking, particularly in physical education and field trips. A striking 91% of 678 teachers in the study stated that colleagues needed further information about diabetes (p. 5). UK primary school teachers have noted being nervous, panicked, terrified, fearful, scared, and dubious when providing school-based diabetic care (Boden et al., 2011).

The possibility of teacher liability for incorrect management or interventive practices was also a concern for school management systems (Boden et al., 2011). School staff in Northern Ireland are the only UK nation protected under statutory law in this instance (Northern Ireland Executive, 2005). Lack of effective training for school staff, particularly classroom teachers, is a widespread theme within this field of research (Faro et al., 2005; Hellems & Clarke, 2007; Lewis, 2003; Melton & Henderson, 2007; Wagner et al., 2006). School staff need to be trained, proficient, and confident when caring for learners with type 1 diabetes to support the child in management of this chronic condition. As stated by the International Society for Pediatric and Adolescent Diabetes (ISPAD, 2018), high-quality diabetic care in schools "is a prerequisite for optimal school performance, including learning, and for the avoidance of diabetes-related complications" (p. 287).

Research Aims and Questions

This systematic review of literature sets out to deliver a review of available evidence on effective and inclusive care management strategies for learners with type 1 diabetes in UK primary schools within the scope of research conducted in the UK, USA, Canada, Australia, and New Zealand. It also aims to make the evidence more accessible to stakeholders and decision-makers, as well as identify potential gaps in current understanding. This required identifying the stakeholders and partnerships involved in care management and determining best practices for school-based care; comparative analysis of the evidence base was useful in achieving this.

Table 1

UK Government Legislation

UK Nation	Legislation	Statutory Guidelines
Scotland	NHS (Scotland) Act (Scottish Government, 1978) Education (Scotland) Act (Scottish Government, 1980)	None
	The Functions of Health Boards - Scotland Order (Scottish Government, 1991)	
	Standards in Schools etc Act (Scottish Government, 2000)	
	Education: Disability Strategies and Pupils Educational Records Act (Scottish Government, 2003) Education: Additional Support for Learning Scotland Act (Scottish Government, 2004)	
	Children and Young Person (Scotland) Bill (Scottish Government, 2014)	
England	Section 3 of the Children Act (UK Government, 1989)	Supporting Pupils with Medical
	Section 17 of the Children Act (UK Government, 1989)	Conditions at Schools (Department for
	The Education Act (UK Government, 2002)	Education, 2014)
	Section 3 of the NHS Act (UK Government 2006)	The Independent School Standards
	Children and Families Act (UK Government, 2014)	Guidance for Independent Schools
		(Department for Education, 2019)
Wales	Additional Learning Needs and Education Tribunal Act (Welsh Government, 2018)	Access to Education and Support for
	The Additional Learning Needs Code for Wales (Welsh Government, 2021)	Children and Young People with
		Medical Needs 2010
Northern	Disability Discrimination Act (Northern Ireland Executive, 1995)	The Supporting Pupils with Medication
Ireland	The Special Educational Needs and Disability Order (Northern Ireland Executive, 2005)	Needs (The Department of Education, 2008)

Also necessary was a review of training opportunities and materials available to primary teachers. Thus, a systematic review of the literature was utilized to generate a response to the following research questions:

- 1. What role do specific stakeholders play in the management of type 1 diabetes in primary schools in the UK?
- 2. What considerations and practices are suggested for effective care and management of learners with type 1 diabetes?
- 3. What training is needed for teachers who care for learners with type 1 diabetes?

Methods

A systematic literature review can be considered "the most reliable and comprehensive summary about 'what works' in a given field" (Van Der Knaap et al., 2008, p. 49) and thus was chosen to achieve the stated aims. Effective reviews require an organized approach to planning and implementation. As recommended by the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI, 2010), data collection methods used in this study can be broadly categorized into three key areas – scope, search, and screening. **Scope**

Inclusion and exclusion criteria (see Table 2) were created according to the research questions to provide a standard for determining eligibility for inclusion (Torgerson & Light, 2012). Criteria included topic, recency, language used, geographical area, age range of subjects, transparency, and dependability of results (Davies et al., 2013). Criteria were grouped and included within four distinct screening protocols.

Table 2

Inclusion Criteria

Criterion type

Inclusion criteria

Topic	Literature used must refer to the research question. Key themes include caring for learners with chronic health conditions in primary schools, diabetic care in schools, creating individual health care plans, collaboration, partnership, and staff training.
Recency	Literature should be published between 2011 and 2021.
Language	Materials written in the English language.
Age-range of subjects	Literature should relate to primary school children.
Geographical spread	Literature should relate to practice in the core Anglosphere.
Transparency and validity	Literature explicitly explores the foundational aspects of the study and findings, e.g., data methods and references used.

Search

The search strategy involved choosing specific databases to obtain literature. Databases included Education Resources Information Centre (ERIC), Journal Storage (JSTOR), and Sage Journals. ERIC was chosen as it is the largest educational database in the world, which increased the likelihood of yielding a large response. Additionally, studies published by JSTOR and Sage Journals are peer-reviewed and provide high-quality and reliable sources. As this study would benefit from the inclusion of government policy and guidelines, materials were also obtained through wider digital searches, namely, grey research from UK government publications of studies and research, policies, and legislation obtained from the following websites: Scottish Government, Department for Education, GOV. UK, and the National Foundation for Educational Research. This approach increased the overall applicability of the study as it relates explicitly to the educational policies of its jurisdiction. Conclusions drawn were more meaningful as they reflected the current standards of UK primary schools. Published books, book chapters, and dissertations were excluded to reduce publication influence and potential bias (Booth et al., 2012). To yield meaningful results from searches, a combination of search terms specific to the research questions and aims were created and tested. The following combination was chosen as it generated the most relevant and viable articles: (chronic health conditions OR type 1 diabetes) AND (primary school OR elementary school).

Screening

Protocol 1: Title, Topic, Recency, and Language

The initial search produced 771 results. After eliminating duplicates, the remaining entries were assessed based on the specified topic criteria. The titles were required to mention either type 1 diabetes, any chronic health condition, and primary/elementary school. This refinement narrowed down the sources to 59, which were then evaluated for recency and language criteria. Consequently, 22 sources were excluded. Additionally, to minimize potential misinterpretation by researchers, it was ensured that all 37 selected sources were in English. These sources then proceeded to Protocol 2.

Protocol 2: Abstract Analysis

The second protocol utilised abstract analysis to further refine the 37 sources. Abstracts were appraised for geographical and age-range criteria. To progress to the next protocol, the articles needed to be based on practice in the core Anglosphere, which included regions of the UK and/or the USA and/or Canada and/or Australia and/or New Zealand. These areas were chosen due to similar approaches to primary education, diabetic healthcare, and the common English language. Material based on the UK provides reference to relevant educational policy and legislation. Broadening the context beyond the UK provided breadth and depth for analysis and application. The inclusion of multiple countries allowed access to additional and specific expertise; 13 sources were excluded based on this criterion. The age range of the participants needed to be situated within primary education; sources focused solely on primary education age, typically 4-12 years, were included. Sources that took a wider scope between 2-18 years were also included as the primary age-range was referenced, but only if explicit reference to the primary setting was made. This ensured studies focused on juvenile onset type 1 diabetes and conclusions could be applied to the primary context. Studies not satisfying criteria were omitted; 24 progressed to the third protocol.

Protocol 3: Relevance Review

This protocol involved a review of relevance for answering the review questions through skimming the full research paper. Sources were analyzed according to key terms of the aims; materials were omitted if there was no explicit mention of school-based setting, staff training and/or resources, individual healthcare plan, or collaboration and partnership. This protocol streamlined the materials to 17 papers, which progressed to Protocol 4.

Protocol 4: Quality Assessment

The fourth protocol refined the search through in-depth reading and quality assurance assessment (Booth et al., 2012). Data were organized in a spreadsheet and involved reflection upon the aforementioned inclusion criteria, which were re-examined, noting validity and clarity. To ensure a high degree of transparency, research upon which the paper was based had to be explicit (e.g., sample size, methods, etc.; Davies, 2013). Sources not deemed transparent were omitted to ensure reliability. Each study was evaluated on the dependability of the results as determined by quality norms for the type of research design utilized in the study (methodological quality), the feasibility of the study design to answer the specific research issue (methodological relevance), and the emphasis as appropriate for answering the review question (topic relevance; Gough, 2007). For further quality assurance, each paper was read in-depth twice. Three articles were omitted as they did not provide adequate research or data to substantiate claims, resulting in 14 papers (see Table 3). Extracted information was later coded and analyzed. While efforts were made to ensure all relevant papers were identified through the review, it is noted that restrictive inclusion criteria have been applied.

Thematic Analysis

A total of 14 sources were deemed suitable for thematic analysis according to Braun and Clarke's (2006) "6 Step Framework", an examination method for identifying, analysing, and reporting patterns within data. Thematic analysis looks beyond the frequency of a given term by identifying and exploring both implicit and explicit ideas (Guest et al., 2012). The analysis process involved the following steps: familiarizing yourself with the data, creating initial codes, searching for themes, reviewing themes, naming themes, and producing the report (p. 87). Employing this process ensured a rigorous, rich, and detailed account of the findings (King, 2004). Each step is iterative and reflective of another, therefore encouraging continuous reflection between phases of analysis (Nowell et al., 2017).

Ethical Considerations

Commensurate with a systematic literature review, ethical considerations relate primarily to researcher bias and transparency of processes for reproducibility. As a primary teacher in Scotland with type 1 diabetes, the first author appreciated how personal experience could be used to understand the research material and empathize with stakeholder groups. However, the incidence and potential influence of researcher bias must be considered. The use of bracketing and reflective practice combated such bias (Creswell, 2007). The use of bracketing involves a thorough, honest, and in-depth personal reflection throughout the research process. Brainstorming, repeated analysis, reintegration of meaning, and reflective journaling ensured that a high level of neutrality was achieved. The creation and adherence of stringent protocols also increased the validity and reliability of the research (Snyder, 2019). Additionally, the initial work of the review was critiqued through the submission of the first author's master's dissertation, which further confirmed the reliability of the research process and findings. During that process, the second author served as dissertation supervisor and a "critical friend" (Herr & Anderson, 2015) who engaged in debriefing conversations with the researcher throughout the data collection and analysis process.

Table 3

Overview of Articles from Systematic Review Protocols

Citation	Research Aims	Research Design	Geographical Context	Role of Stakeholders	Collaborative Working	Training	Pupil self- management	Individual Care Plans
American Diabetes Association, 2013	To review current guidelines and the responsibilities of various stakeholders in caring for learners with type 1 diabetes.	Qualitative Position statement of the American Diabetes Association	USA	Х	X	Х	Х	x
Association of Diabetes Care and Education Specialists, 2016	To review current practices to ensure effective school-based care for learners with type 1 diabetes.	Qualitative Position statement from the Association of Diabetes Care and Education Specialists	USA	Х	X	Х	Х	X
Bobo et al., 2011	To review the Healthy Learner Model and its potential to provide effective and consistent care for learners with type 1 diabetes.	Qualitative field research; 5-year Based on 2 schools Interviews and surveys	USA		Х	Х		Х
Department for Education, 2015	To blend educational policy, legislation, and research-based recommendations to be used by schools, local authorities, parents/carers, pupils, and health service	Qualitative Grey literature - statutory legislation References to research	UK	Х	Х	Х	Х	Х

	providers to ensure effective care for young people with medical conditions.							
Edwards et al., 2014	To review interventions and barriers on the path to achieve optimal diabetes self-care and management.	Mixed-methods systematic review Based on 66 studies	USA	Х	Х	Х	Х	Х
Fried et al., 2020	To analyze strategies used to care for learners with type 1 diabetes in schools in Western Australia.	Qualitative Maximum variation sampling; staff, students, and their parents; mixed setting 10 schools Semi-structured interviews	Australia	Х	X	X	Х	Х
Hinton & Kirk, 2014	To explore barriers and supports when catering for learners with chronic health conditions and to review training materials and interventions for best practice.	Qualitative Systematic review Based on 61 studies Explicit method outlined	UK	Х	X	X		X

Hopkins & Hughes, 2016	To explore the use of individual health care plans and their benefits in educational settings when catering for learners with chronic health conditions.	Qualitative Case study of 'Jordan' and those involved in his care - parents, teacher, school management, nurse, etc.	USA	Х	х			Х
Jackson et al., 2015	To review and suggest diabetes management strategies for learners with type 1 diabetes in elementary and secondary settings.	Qualitative Position statement from the American Diabetes Association	USA	Х	Х	Х	Х	Х
Lawrence et al., 2015	To review current policy and practice to ensure safe and fair treatment of learners with type 1 diabetes.	Qualitative Position statement from the Canadian Paediatric Society Review of literature and legislation	Canada		X	Х	х	Х
MacMillan et al., 2014	To explore supports and barriers for learners with type 1 diabetes when engaging with Physical Education in school settings.	Qualitative Field research; interviews, and focus groups Scottish setting Mix primary and secondary; 8, 7–9 year-olds and 8, 12-14 year-olds	UK		X	Х		X

Marshall, 2017	To review stakeholder roles when catering for learners with type 1 diabetes.	Qualitative Case studies 19 participants from 2 primary schools in the north of England	UK	Х	Х	Х	Х
Marshall et al., 2013	To examine the role of nurses and other health care practitioners in supporting learners with type 1 diabetes in early year settings and schools.	Qualitative Field research Focus groups and interviews 47 participants	UK	Х	Х	Х	Х
National Health Service, 2017	To enable schools to manage learners with type 1 diabetes effectively in a school setting.	Qualitative National guidance created by several organizations - University College London Hospitals, the Hillingdon Hospital, and from stakeholders Uses high-quality sources	UK	Х	Х	Х	Х

Findings

Fourteen papers were included in the review. Key characteristics and aims of each paper are outlined in Table 3. All sources share the overarching vision of ensuring adequate provisions for learners with type 1 diabetes or other chronic health conditions in primary school settings. In line with the inclusion criteria, sources reflect school practices of Australia (n = 1), Canada (n=1), the UK (n = 6) and the USA (n = 6). A blend of research methodologies was utilized in the research, including interviews and focus groups (n = 2), surveys and interviews (n = 1), interviews (n = 1), case studies (n = 2), systematic literature reviews (n = 2) and grey research based on high-quality and referenced sources (n = 6). Literature was first reviewed and coded, and then themes were created (Braun & Clark, 2006). Themes were later revised, named, and defined. As a result, the following key elements of effective and inclusive school-based care were identified: clear roles of key stakeholders, promoting collaborative working, providing adequate training opportunities for school staff, facilitating learner self-management, and the use of individual healthcare plans. Findings are presented according to the research questions.

Stakeholder Roles

Identifying and delegating stakeholder roles was recognized as an effective strategy for school-based diabetic care. Supporting and caring for a learner with type 1 diabetes is not the sole responsibility of a single stakeholder (DfE, 2015; Fried et al., 2020; Marshall, 2017). According to DfE (2015) and NHS (2017) guidelines, headteachers are responsible for creating and reviewing medical conditions policies, which should incorporate the listing of designated staff members and their specified roles; furthermore, the headteacher is tasked with the creation and review of individual care plans and emergency plans, as outlined in the DfE (2015) guidelines. It was noted that schools, led by the headteacher, have the responsibility of creating a safe space by ensuring immediate access to hypoglycaemic treatment, a private location to carry out procedures, if desired by the learner, and an appropriate location for equipment storage and disposal (ADA, 2013; Edwards et al., 2014; Jackson et al., 2015; MacMillan et al., 2014). Continuity in lesson timetables is also suggested to ensure treatment coincides with physical education schedules (MacMillan et al., 2014). Accommodations may also be required for examinations, tests, and quizzes (Fried et al., 2020; Jackson et al., 2015; Lawrence et al., 2015). This may include keeping an emergency box on their desk and/or additional time if the learner experiences a hypoglycaemic or hyperglycaemic episode (Lawrence et al., 2015). All details should be included in school policy and care plans.

It was also found that teachers lack clarity regarding their role in school-based diabetic care (Hinton & Kirk, 2014). Teachers working in the UK usually volunteer to assist learners with type 1 diabetes and are not legally obliged to administer insulin or carry out blood glucose monitoring (Hinton & Kirk, 2014). Trained staff are responsible for carrying out or supervising blood glucose testing, insulin calculation, and administration; it is recommended that trained staff work in partnership with the home and observe the parent/guardian in such roles (NHS, 2017).

School nurses in American contexts are responsible for coordinating and leading school-based care (ADCES, 2016). All schools in the UK have access to school nursing services outside of the school context through the National Health Service (DfE, 2015, p. 14). In the UK, school nurses are responsible for informing a school if a learner requires schoolbased support; they may act as a key liaison between school staff and diabetic specialists (DfE, 2015).

The learner with diabetes should be included in all decision-making practices and encouraged to self-manage their condition to a degree appropriate to their development and experience (DfE, 2015; Edwards et al.c, 2014; Jackson et al., 2015; NHS, 2017). Such duties are subject to parental consent and a risk assessment (NHS, 2017). The learner's individual care plan should specify explicitly the extent of the learner's self-management duties (NHS, 2017).

In the UK, the parent/guardian is legally responsible for liaising with the school and healthcare services to provide up-to-date information and resources (DfE, 2015; NHS, 2017). They supply and maintain all supplies, equipment, food schedules, insulin regimes, and current emergency contacts (ADA, 2013; Jackson et al., 2015; NHS, 2017). Creating a "Go Bag" containing all relevant supplies, equipment, and protocols identified in the learner's individual care plan is recommended to support practice (Hopkins & Hughes, 2016, p. 39). Several studies highlighted a dependency on parental involvement for school trips (Edwards et al., 2014). It was also noted that parents who were required to attend school for insulin administration and/or field trips experienced a restricted lifestyle (Marshall et al., 2013).

Diabetes specialists are responsible for training and upskilling all school staff, including school nurses (ADCES, 2016). They should also provide resources and expertise to support school staff (p. 2) and be involved in creating and reviewing individual care plans (ADA, 2013; ADCES, 2016; DfE, 2015). Clinical Commissioning Groups are composed of nurses and other clinicians specializing in diabetic care and are responsible for reviewing and supporting current school-based care by providing resources and information (DfE, 2015).

Considerations and Practices for Effective Care and Management

The use of individual healthcare plans, promoting collaborative working between stakeholders, and enabling pupil self-care were noted as key practices and elements of effective diabetic care in primary schools.

Individual Healthcare Plans

An individual healthcare plan should be developed for each learner with diabetes (Lawrence et al., 2015). It ensures that learners are adequately supported by providing clarity on all aspects of school-based care (DfE, 2015). This practice aims to capture the necessary steps a school must take to support learners (DfE, 2015). Discussions between school staff, parents/guardians, the learner, and healthcare professionals should be used in the creation and review of the plan (ADCES, 2016; DfE, 2015; Edwards et al., 2014; Jackson et al., 2015; Lawrence et al., 2015; MacMillan et al., 2014; NHS, 2017).

The care plan should name all relevant stakeholders, identify their roles in care (DfE, 2015; Hopkins & Hughes, 2016; Jackson et al., 2015; Lawrence et al., 2015; NHS, 2017), specify the type of insulin, and the individual's regime (Bobo et al., 2011; Jackson et al., 2015; NHS, 2017). The frequency and circumstances requiring blood glucose monitoring, insulin administration, ketone check, or a bolus should be stated (ADA, 2013). Descriptions of the learner's specific presentation of hypoglycaemia and hyperglycaemia should be included alongside the protocol for intervention (NHS, 2017). Required equipment (e.g., glucometer) and medication should be noted alongside the recommended dose (DfE, 2015).

Considerations for physical education or general exercise should also be included. This should refer to blood glucose testing, additional snack requirements, and insulin adjustments (Fried et al., 2020; Jackson et al., 2015; NHS, 2017). The plan should include emergency contact numbers and scenario descriptors requiring emergency services (DfE, 2015; NHS, 2017). Emergency, contingency, and school trip plans should be included (DfE, 2015; Fried et al., 2020; NHS, 2017). All stakeholders should agree upon the review date of the plan. Regular review, at least annually, is recommended to ensure practice reflects the learner's current requirements (DfE, 2015; NHS, 2017). Edwards et al. (2014) concluded the use of care plans improves a learner's experience of school by limiting disagreements regarding care. They are also considered an effective tool for gathering and sharing information within a multidisciplinary team (Hopkins & Hughes, 2016; Marshall et al., 2013). Hinton and Kirk (2014) stated that individual care plans are not consistently used in the UK. While individual care plans are not required by law, they are highly recommended to support learners (Hopkins & Hughes, 2016).

Collaborative Working

Open lines of communication between health services, the learner with diabetes, their family, and school personnel are essential for promoting the learner's success and safety in school (American Diabetes Association [ADA], 2013; Association of Diabetes Care and Education Specialists [ADCES], 2016; Bobo et al., 2011; Hopkins & Hughes, 2016; MacMillan et al., 2014; Marshall, 2017). Several papers focus predominately on the relationship between the school and healthcare services as a vital aspect of diabetic care (Department for Education [DfE], 2015; Edwards et al., 2014; Marshall et al., 2013). Schools should establish positive working relationships with diabetic healthcare providers and should be enabled to contact relevant agencies if needed (DfE, 2015; Edwards et al., 2014; Marshall et al., 2013). It is recommended to schedule regular appointments with diabetic care providers regarding the management needs of each learner (Bobo et al., 2011; Hopkins & Hughes, 2016). However, it has been stated that such healthcare providers were "often difficult to reach and were too busy to respond to questions" (Edwards et al., 2014, p. 20). Communication between the school and outside agencies is necessary to overcome healthcare concerns. The school nurse has been identified as a key point of communication, particularly in American-based studies (ADA, 2013; ADCES, 2016; Edwards et al., 2014).

Hopkins and Hughes (2016) lament that parents must be considered a primary source of information. Effective partnership between the home, school, and healthcare specialists enables seamless management between contexts (Bobo et al., 2011). Parents/guardians stated that improved lines of communication between healthcare providers and school personnel would mitigate their concerns regarding school-based care (Hopkins & Hughes, 2016). Several sources speak of the negative impact of poor communication between parents/guardians and schools. Relying on parental input for school-based care may be problematic as school staff may feel uncomfortable highlighting their concerns and uncertainty (Hinton & Kirk, 2014). Fried et al. (2020) also stated that a lack of routine continuity affected school-based care, for example, when students came to school without breakfast. To improve communication between stakeholders, it is suggested to agree on and adhere to a preferred methods (e.g., email) (Bobo et al., 2011).

Promoting Learner Autonomy and Self-Management

Encouraging learners to become more independent in the management of their chronic condition was recognized by several sources. These learners should be encouraged to participate in the management to the extent appropriate to their development (ADA, 2013; Jackson et al., 2015; Lawrence et al., 2015). This ownership should be discussed and agreed upon by parents/guardians, diabetic specialists, and school staff (ADA, 2013; ADCES, 2016; Jackson et al., 2015). School policies should cover arrangements for learners competent in self-care (DfE, 2015); learner-specific duties should be outlined in the individual care plan (ADA, 2013). The learner and their readiness to lead their care should be reviewed annually (ADCES, 2016). The learner's willingness and capacity to use self-management strategies should be respected (ADA, 2013; Jackson et al., 2015). Depending on the capability and maturity of the learner, they may be able to perform blood glucose checks with adult supervision (Jackson et al., 2015; Lawrence et al., 2015). Older primary school learners may be capable of self-administering insulin with adult supervision (Jackson et al., 2015; Lawrence et al., 2015). The incidence of hypoglycemia unawareness should also be considered when encouraging self-management strategies (ADA, 2013; Jackson et al., 2015).

Training and Support Materials for Primary Teachers

It is widely reported that teachers have limited knowledge of type 1 diabetes and do not receive adequate training and support (Fried et al., 2020; Hughes & Hopkins, 2016; Jackson et al., 2015; MacMillan et al., 2014; Marshall et al., 2013). The healthcare needs, when and how to administer medication, and recognizing symptoms of hypoglycaemic and hyperglycaemic episodes are of utmost concern (Edwards et al., 2014; Hinton & Kirk, 2014; MacMillan et al., 2014). Teacher attitudes towards caring for learners varied amongst those interviewed and surveyed. Several teachers were noted as feeling shocked, worried, frustrated, and fearful of making mistakes (Hinton & Kirk, 2014; Hughes & Hopkins, 2016).

School management systems should ensure that all training and resources are outlined in school policies (ADA, 2013; DfE, 2015). Training should be targeted to all staff responsible for learner care, including teaching staff, support staff, administrative staff, management, school nurses, and bus drivers (ADA, 2013; Edwards et al., 2014; Jackson et al., 2015). A first-aid certificate is not an adequate qualification for caring for learners with type 1 diabetes (DfE, 2015). It is recommended that practical, hands-on training is needed alongside theoretical sessions to improve staff knowledge and increase confidence in responding to emergencies (MacMillan et al., 2014).

Healthcare professionals should review the proficiency levels of school staff and respond accordingly to ensure high-quality care (DfE, 2015), and relevant materials should be provided to support practice (ADA, 2013). Training should include recognizing and treating hypoglycemia and hyperglycemia, managing exercise, record keeping, calculating and administrating insulin, and monitoring glucose levels (ADCES, 2016; Edwards et al., 2014; Lawrence et al., 2015; NHS, 2017). Annual training should be provided to schools (NHS, 2017; Marshall et al., 2013), and student-specific training should be provided by specialist services (ADCES, 2016; Edwards et al., 2014). Staff should also be trained to respond in emergencies (e.g., glucagon administration) (DfE, 2015; Lawrence et al., 2015).

Fried et al. (2020) reported a lack of a standardized approach to staff training. Hinton & Kirk (2014) also highlighted that teachers received little formal training when catering to learners with chronic health conditions and may be required to engage in self-directed training using the internet and leaflets. A three-tiered approach is recommended by several American-based studies (ADA, 2013; Jackson et al., 2015), which involves all staff receiving foundational training, staff directly involved with the child's care receiving additional training, and those leading school-based care receiving specialist training.

Discussion

As teachers have raised concerns about effective, school-based diabetic care, findings from this systematic review are situated to address implementation concerns of statutory guidelines, aid decision-making according to inclusive best practices, and make vital information accessible to teachers. Findings point toward necessary changes in practice specific to three of the key stakeholders: the school nurse, the child, and the teacher.

Focus on The School Nurse

It is evident from the review the role and availability of school nurses in the UK should be re-examined to ensure learners and their teachers are well supported in providing holistic care. Studies have shown the role of school nurses differs greatly between the UK and the USA, stemming from placement, availability, and utilization. In sharp contrast, 52% of schools in the USA had a full-time nurse, and 82% had at least one full-time or part-time nurse in the 2015-2016 academic year (Institute of Education Sciences, 2020). School nurses in the USA function as a leader and coordinator of school-based care (Council on School Health, 2008). School nurses in the UK are referred to as Specialist Community Public Health Nurses (SCPHN); their roles in school contexts are exceptionally diverse, with their services being stretched and under resourced (Hoekstra et al., 2016). The number of school

nurses in UK nursery, primary, and secondary school settings has fallen 30% since 2010, with about 2,100 nurses working across 32,113 schools (Miller, 2019).

Specifically related to their role in school-based diabetic care, school nurses are liaisons between the school, family, and specialist services, provide essential training to school staff, and contribute and review healthcare plans (East of England Paediatric Diabetes Network [EAPDN], 2014). Paediatric Diabetes Specialist Nurses work within the child's diabetes care team and play a larger role in organizing and ensuring care. Although individual healthcare plans are not mandated by law in the UK, developing, planning, and utilizing these plans creates a safe space for learners and clear care requirements (Hopkins & Hughes, 2016). Findings from this review indicated an individual healthcare plan is widely recommended as effective care management (see exemplar in Author, 2023). However, a survey based on UK practice showed plans are not routinely used in schools (Hinton & Kirk, 2014).

Educational policy within the Scottish context states that parents/guardians have the right to request an individualized health plan (IHP). The difference between an IHP and an Education, Health, and Care Plan (EHCP) should be noted. An EHCP is a "legally binding document that describes all of the special education, health and care needs of the child or young person which relate to their disability" (UK Government, n.d.). This plan needs to be applied for and granted on an individual basis by governing local authorities, and detailed support given beyond what a school can provide. In further contrast to the UK setting, school nurses in the USA are typically positioned onsite and are enabled to provide immediate care and support (Council on School Health, 2008). This highlights an urgent need to review UK legislation and practices, specifically the roles and availability of school nurses, as all children are entitled to receive appropriate support (UNESCO, 2017). Lack of school staff knowledge and resulting negative attitudes toward caring for learners threaten the

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actualization of these learners receiving appropriate support at school (Boden et al., 2012). If the roles of school nurses in the UK were adapted to exist primarily within the school, the pressure on school staff to provide medical care could be negated, and learners would receive the necessary support.

Communication between the school nurse and outside healthcare agencies is necessary to ensure effective diabetes management and may provide a missing element to holistic care of chronic conditions. The research highlighted that healthcare providers were "often difficult to reach and were too busy to respond to questions" (Edwards et al., 2014, p. 20). Therefore, communication methods should also be established, noted in the individual healthcare plan, and adhered to. Emergency plans should be made available in the event of an acute concern (Author, 2023). Creating contingency plans for extra-curricular activities may also reduce an over-reliance on healthcare professionals while upholding the learner's right to fully participate in the totality of educational experiences. These plans are integral to ensuring primary schools in the UK uphold the legal responsibility of enabling learners to participate in all educational experiences in a safe and secure manner (DfE, 2015).

An increase in nursing support to underpin mandated healthcare plans may improve both the consistency and quality of care. It may also limit inequities in care reflective of the jurisdiction and governing policies in the child's macro-level ecological context. The implications of such a directive need to be carefully considered; while policy revision would provide a framework for diabetic care, it may also incur additional difficulties for schools. Challenges may include arranging regular meetings for stakeholders, which could result in school-based care being agreed to unanimously. This change in approach may also catalyze a review of policy and care requirements for other chronic health conditions in school contexts (e.g., asthma or epilepsy).

Focus on The Child

Encouraging learners with diabetes to self-manage their condition is recognized in the literature as an inclusive practice and effective strategy for positive long-term management. Learners should be encouraged and facilitated to participate in their care to an extent that is developmentally appropriate (ADA, 2013; Jackson et al., 2015; Lawrence et al., 2015). This drive to promote self-management in schools is highly reflective of empowerment education; inspired by the works of Freire (1970), empowerment education is considered a health education model to promote health in social environments. With specific links to selfmanagement and education of a person with diabetes, empowerment education can be defined as "the discovery and development of one's inherent capacity to be responsible for one's own life" (Funnell & Anderson, 2003, p. 454). By including the learner in managing their condition, for example, through discussion and the distribution of appropriate roles, the learner is more likely to feel greater control over their own life (Carvalho, 2004). However, the degree of self-management responsibility relates to the learner's cognitive skills and emotional maturity required (De Cássia Sparapani, 2017). If successful, this management style can result in empowered learners with sufficient knowledge to make rational decisions (Funnell & Anderson, 2003, p. 454). This approach encourages learners with diabetes to develop their capacities and skills to recognize and meet their medical needs. Scotland's Getting it Right for Every Child (GIRFEC) framework is pertinent to the aims of empowerment education (Scottish Government, 2006). This child-focused framework identifies and responds to a learner's set of needs and involves a team of stakeholders working in tandem for the benefit of the learner's wellbeing (ibid).

Inclusion of students with diabetes should "be guided by the principle of only as special as necessary to nurture the dignity, independence, and autonomy of the learner" (Fried et al., 2020, p. 518; Lawrence et al., 2015). The least restrictive environment (LRE) is one of the six fundamental principles of the USA Individuals with Disabilities Education Improvement Act (IDEA) (Marx et al., 2014); linking this concept to school-based care, LRE refers to roles within a multidisciplinary team and clearly outlining aspects of care within a school-based healthcare plan. Each nation of the UK is committed to ensuring learners develop the knowledge and life-long skills needed for positive personal wellbeing as shown through respective curricula. For example, within Scotland's Health and Wellbeing area of the Curricula for Excellence, learners can "demonstrate how to keep themselves safe and how to respond in a range of emergency situations" (Scottish Government, 2009, p. 3). Learners should be encouraged to develop self-management strategies with the aim of nurturing independence, competence, and confidence in caring for their condition. This practice is linked to increased levels of self-efficacy, which results in better adherence to medical plans, positive health outcomes, and a LRE (Landers et al., 2015). The wellbeing indicators of Safe, Healthy, Achieving, Nurtured, Active, Responsible, Respected, and Included (SHANARRI) are also relevant (Education Scotland, 2021) and an example of supportive, pupil-centred policy in the UK. Learners with diabetes should be appropriately supported to ensure these eight factors of wellbeing are actualized in all jurisdictions.

To encourage self-management strategies, learners could engage with diabetes education and self-management support. However, despite the recommendation of diabetic education courses for children, few supports exist within the UK. The Dosage Adjustment for Normal Eating (DAPNE) program (2021) is a structured course targeted explicitly at adults, which explores fundamental aspects of the condition. However, a course like DAPNE could be useful and adapted for learners beginning to lead their care. Alternative supports offered within the UK context include child-orientated, paper-based guides (Diabetes.org.uk and JDRF.org.uk). The Juvenile Diabetes Research Foundation released an initiative called KIDSAC for young children with type 1 diabetes, which encourages children to learn and develop self-management strategies (JDRF, 2021b). Yet effective self-management requires a holistic and seamless approach to improve learner outcomes. Roles and responsibilities of the pupil should be clearly outlined in management meetings and indicative of school policies and healthcare plans. Furthermore, parents/guardians should be acutely aware of their role in school-based care and supporting pupil autonomy. A weekly checklist may be a useful tool in ensuring all parental duties are performed (Author, 2023). While parents retain primary responsibility for medicine administration, current UK legislation states that parents/guardians should not be expected to provide daily diabetic care during school hours (Diabetes UK, n.d.). This strategy would solidify the role of parents/guardians in school-based care in a clear and concise manner. Since self-management is directly affected by communication between the home, school, and medical practitioners, preferred means of one-way and two-way communication should be agreed upon (Bobo et al., 2011) and noted in the healthcare plan (Author, 2023).

Focus on The Teacher

Teachers need to be prepared *about*, and *for* diabetes care. This review confirmed knowledgeable staff is required to create a safe school environment (ADA, 2013; Jackson et al., 2015), yet there remains no standardized approach to diabetes education for educators. Teachers who have a child with any chronic condition in their classroom need information about the condition and how to provide care as well as make educationally appropriate decisions (e.g., curriculum, pedagogy, assessment). Schools retain responsibility in ensuring all relevant staff receive appropriate training and support, details of which should be outlined in school policies with proficiency levels reviewed by healthcare professionals on an ongoing basis (ADA, 2013; DfE, 2015). Pupil-specific training should be provided due to individual presentations of diabetes (ADCES, 2016; Edwards et al., 2014), and training materials for pupils in self-management could also be used to develop teacher understanding.

There is an opportunity to improve practices by employing a strategy similar to the three-tiered level training used in the USA (ADA, 2013; Jackson et al., 2015). This approach involves all staff receiving basic training and those more integrally involved receiving specialist training. There are free basic and advanced e-learning modules from UK-based agencies for individual staff use (JDRF, 2021d). However, research recommends a blend of theory and practical training approaches to support knowledge acquisition and application (MacMillan, 2014), a role perhaps a school nurse may fulfill.

Limitations

Although efforts have been made to address the constraints of the systematic review, limitations of this approach were anticipated and must be addressed. The presentation and nature of type 1 diabetes should first be appreciated. As the experiences and requirements of diabetes vary, it can be difficult to produce a one-size-fits-all approach to school-based care. Each learner requires individualized care reflective of their personal presentation. A rigid management plan may not produce an adequate level of diabetic care; therefore, it is important to consider the flexibility of suggestions and conclusions. Results and findings obtained through a systematic literature review are only as reliable as the methods adopted in the original primary research. Consequently, any inherent issues in research design remain and may have influenced results.

This study compared practices within countries in the core Anglosphere. Exploring practice within the European Union may be insightful for future studies. The Euro Diabetes Index 2014 ranked the countries of the European Union plus Norway and Switzerland in terms of specific criteria. This included "prevention, case finding, range and reach of services, access to treatment/care, procedures and outcomes" (Health Consumer Powerhouse, 2014). Sweden ranked first in the study, whereas the UK ranked fourth. While this study

focused on diabetic care through a medical lens, it may prove beneficial to explore how diabetic care is provided in European primary schools.

Conclusion

This review has identified a variety of foci for effectively supporting learners with type 1 diabetes in UK primary schools. Five core aspects of inclusive and effective schoolbased diabetic care were identified as successful practices. These included identifying and delegating the roles of key stakeholders, collaborative working between stakeholders, adequate training opportunities for school staff, facilitating appropriate learner selfmanagement, and the creation and review of individual healthcare plans. All aspects of school-based care must coincide and uphold stipulations from governing policy and legislative regulations.

Each UK home nation hosts a distinct set of educational policies and guidelines aiming to both guide best practices and protect the rights of learners. The need for clear guidelines is increasingly important to ensure effective school-based care. A lack of a nationwide and standardised policy relating to the care of learners with medical conditions may be contributing to high-levels of school staff uncertainty in their role. These issues need to be rectified to ensure we provide inclusive and effective care for children in every classroom.

References

- American Diabetes Association (ADA). (2013). Diabetes care in the school and day care setting. *Diabetes Care, 36*(1), 75-79. <u>https://doi.org/10.2337/dc13-S075</u>
- Association of Diabetes Care and Education Specialists (ADCES). (2016). *Management of children with diabetes in the school setting*. Retrieved November 28, 2021, from <u>https://www.diabeteseducator.org/docs/default-source/practice/practice-</u> <u>documents/position-statements/management-of-children-with-diabetes-in-the-school-</u>

setting.pdf?sfvrsn=4

- Atkinson, M. A., Eisenbarth, G. S., & Michels, A. W. (2014). Type 1 diabetes. *The Lancet*, 383(9911), 69–82. <u>https://doi.org/10.1016/s0140-6736(13)60591-7</u>
- Bobo, N., Kaup, T., McCarty, P., & Carlson, J. P. (2011). Diabetes management at school:
 Application of the healthy learner model. *The Journal of School Nursing*, 27(3), 171-184.
 https://doi.org/10.1177/1059840510394190
- Boden, S., Lloyd, C. E., Gosden, C., Macdougall, C., Brown, N., & Matyka, K. (2011). The concerns of school staff in caring for children with diabetes in primary school. *Pediatric Diabetes*, *13*(6), 6-13. <u>https://doi.org/10.1111/j.1399-5448.2011.00780.x</u>
- Booth, A., Papaioannou, D., & Sutton, A. (2012). Systematic approaches to a successful literature review. Sage.
- Brands A. M., Biessels G. J., De Hana E. H., L Kappelle, J., & Kessels, R. P. (2005). The effects of type 1 diabetes on cognitive performance: A meta-analysis. *Diabetes Care*, 28(3), 726–735. http://dx.doi.org/10.2337/diacare.28.3.726
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. <u>http://dx.doi.org/10.1191/1478088706qp063oa</u>
- Bronfenbrenner, U. (1979). Contexts of child rearing: Problems and prospects. *American psychologist*, *34*(10), 844-850. <u>http://dx.doi.org/10.1037/0003-066X.34.10.844</u>

- Carvalho, S. R. (2009). Education for type 2 diabetes mellitus self-care: From compliance to empowerment. *Comunicação Saúde Educação*, 13(30), 93-106. <u>http://dx.doi.org/10.1590/S1414-32832009000300009</u>
- Council on School Health. (2008). Role of the school nurse in providing school health services. *Pediatrics*, 121(5), 1052-1056. <u>https://doi.org/10.1542/peds.2008-0382</u>
- Creswell, J. W. (2007). *Qualitative inquiry & research design: Choosing among five traditions* (2nd ed.). Sage.
- Davies, D., Jindal-Snape, D., Collier, C., Digby, R., Hay, P., & Howe, A. (2013). Creative learning environments in education: A systematic literature review. *Thinking skills and creativity*, 8, 80-91. <u>https://doi.org/10.1016/j.tsc.2012.07.004</u>
- De Cássia Sparapani, V., Liberatore, R., Damiăo, E. B. C., Oliveira Dantas, I. R., De Camargo, R. A. A., Nascimento, L. C. (2017). Children with type 1 diabetes mellitus: Selfmanagement experiences in school. *Journal of School Health*, 87(8), 623-629. https://doi.org/10.1111/josh.13289
- Department for Education (DfE). (2015). Supporting pupils at school with medical conditions: Statutory guidance for governing bodies of maintained schools and proprietors of academies in England. Retrieved November 21, 2021

from <u>https://assets.publishing.service.gov.uk/government/uploads/system/upl oads/attachmen</u> t_data/file/803956/supporting-pupilsat-school-with-medicalconditions.pdf

The Department of Education (DFE). (2008). *Supporting pupils with medical needs*. Retrieved November 28, 2021 from <u>https://www.education-</u>

ni.gov.uk/sites/default/files/publications/de/supporting-pupils-with-medical-needs.pdf

Department for Education (DFE). (2019). The independent school standards guidance for independent schools. Retrieved November 28, 2021 from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data /file/800615/Independent School Standards- Guidance 070519.pdf

- Diabetes UK. (n.d.). Your responsibilities as a teacher or trained member of staff. Retrieved November 28, 2021 from <u>https://www.diabetes.org.uk/guide-to-diabetes/your-child-and-diabetes/schools/school-staff/responsibilities-teachers</u>
- Dosage Adjustment for Normal Eating (DAFNE). (2021). *What is DAFNE?* Retrieved November 28, 2021 from <u>https://dafne.nhs.uk/about-dafne/what-is-dafne</u>
- East of England Paediatric Diabetes Network. (2014). *Diabetes guidelines for schools, colleges* & early years settings. Retrieved November 28, 2021 from <u>https://jdrf.org.uk/wp-</u> <u>content/uploads/2015/11/Guidelines-for-schools-colleges-and-early-years-settings2.pdf</u>
- Education Scotland. (2021). *Getting it Right for Every Child (GIRFEC): Wellbeing (SHANARRI)*. <u>https://www.gov.scot/policies/girfec/wellbeingindicators-shanarri/</u>
- Edwards, D., Noyes, J., Lowes, L., Llinos-Haf, S., & Gregory, J. W. (2014). An ongoing struggle:
 A mixed-method systematic review of interventions, barriers and facilitators
 to achieving optimal self-care by children and young people with type 1 diabetes
 in educational settings. *BMC Pediatr*, *14*(228), 1-27. <u>https://doi.org10.1186/1471-2431-14-</u>228
- Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre). (2010). *Methods for conducting systematic reviews*. <u>https://eppi.ioe.ac.uk/cms/Default.aspx?tabid=67</u>
- Falvey, J., & Anderson, S. K. (2023). Meeting the needs of learners with type 1 diabetes in UK primary schools: A systematic literature review of comparative practices Appendices A-F.
 Retrieved 23 December 2023 from:

https://www.gla.ac.uk/schools/education/staff/sarahanderson/#publications,articles

- Faro, B., Ingersoll, G., Fiore, H., & Ippolito, K. S. (2005). Improving students' diabetes management through school-based diabetes care. *Journal of Pediatric Health Care*, 19(5), 301–308. https://doi.org/10.1016/j.pedhc.2005.03.004
- Fried, L., Cross, D., Jones, C., Davis, J. (2020). Lessons from schools with high levels of support for students with type 1 diabetes: A qualitative study. *Issues in Educational Research*, 30(2), 512-531.
- Freire, P. (1970). Pedagogy of the oppressed. Continuum.
- Funnell, M. M., & Anderson, R. M. (2004). Empowerment and self-management of diabetes. *Clin. Diabetes*, 22(3), 123-127. <u>https://doi.org/10.2337/diaclin.22.3.123</u>
- Gough, D. (2007). Weight of evidence: A framework for the appraisal of the quality and relevance of evidence. Special Edition of Research Papers in Education, 22(2), 213–228. https://doi.org/10.1080/02671520701296189
- Graham-Clay, S. (2005). Communicating with parents: Strategies for teachers. *School Community Journal*, *15*(1), 117-129.
- Gutzweiler, R. F., Neese, M., & In-Albon, T. (2020). Teachers' perspectives on children with type 1 diabetes in German kindergartens and schools. *Diabetes Spectrum*, 33(2), 201-209. https://doi.org/10.2337/ds19-0054
- Hellems, M. A., & Clarke, W. L. (2007). Safe at school: A Virginia experience. *Diabetes Care*, 30(6), 1396–1398. https://doi.org/10.2337/dc07-0121
- Herr, K., & Anderson, G. L. (2015). *The action research dissertation: A guide for students and faculty*. Sage.
- Hershey T., Bhargava N., Sadler M., White, N. H., & Craft, S. (1999). Conventional versus intensive diabetes therapy in children with type 1 diabetes: Effects on memory and motor speed. *Diabetes Care*, 22(8), 1318–1324. <u>https://doi.org/10.2337/diacare.22.8.1318</u>

- Hinton, D., & Kirk, S. (2014). Teachers' perspectives of supporting pupils with longterm health conditions in mainstream schools: A narrative review of the literature. *Health & Social Care in the Community*, 23(2), 107–120. <u>https://doi.org/10.1111/hsc.12104</u>
- Hoekstra, B. A., Young, V. L., Eley, C. V., Hawking, M. K. D., & McNulty, C. A. M. (2016).
 School nurses' perspectives on the role of the school nurse in health education and health promotion in England: A qualitative study. *Nursing*, *15*(73), 1-9.
 https://doi.org/10.1186/s12912-016-0194-y
- Hopkins, A. F., & Hughes, M. (2016). Individualized healthcare plans: Supporting children with chronic conditions in the classroom. *Young Exceptional Children*, 19(2), 33–44.
 https://doi.org/10.1177/1096250614566538
- International Diabetes Federation (IDF). (2019). *Diabetes atlas: 9th Edition*. Retrieved November 28, 2021 from
 - https://www.diabetesatlas.org/upload/resources/material/20200302_133351_IDFATLAS9efinal-web.pdf#page=38&zoom=auto
- Institute of Education Sciences. (2020). School nurses in US public schools. Retrieved November 28, 2021 from https://nces.ed.gov/pubs2020/2020086.pdf
- Jackson, C. C., Albanese-O'Neill, A., Butler, K. L., Chiang, J. L., Deeb, L. C., Hathaway, K., Kraus, E., Weissberg-Benchell, J., Yatvin, A. L., & Siminerio, L. M. (2015). Diabetes care in the school setting: A position statement of the American Diabetes Association. *Diabetes Care*, *38*(10), 1958–1963. <u>https://doi.org/10.2337/dc15-1418</u>
- JDRF.org.uk (2021a). *Type 1 diabetes facts and figures*. Retrieved November 28, 2021 from <u>https://jdrf.org.uk/information-support/about-type-1-diabetes/facts-and-figures/</u>
- JDRF.org.uk (2021b). *KIDSAC: A pack for children with type 1 diabetes*. Retrieved November 28, 2021 from <u>https://jdrf.org.uk/information-support/newly-diagnosed/information-packs-and-leaflets/kidsac-pack-children-type-1-diabetes/</u>

- JDRF.org.uk (2021c). *Type 1 diabetes discovery days*. Retrieved November 28, 2021 from https://jdrf.org.uk/information-support/newly-diagnosed/type-1-diabetes-discovery-days/
- JDRF.org.uk (2021d) *Schools E-learning module*. Retrieved November 28, 2021 from <u>https://jdrf.org.uk/for-professionals/school-pack/schools-e-learning-module/</u>
- Jefferies, C., Rhodes, E., Rachmiel, M., Chizo, A. J., Kapellen, T., Abdulla, M. A., & Hofer, S. E. (2018). ISPAD clinical practice consensus guidelines 2018: Management of children and adolescents with diabetes requiring surgery. *Pediatric Diabetes*, 19, 227-236. https://doi.org/10.1111/pedi.12733
- Kengne, A. P. (2012). Special report from the 2011 International Diabetes Federation. *Cardiovascular Journal of Africa, 23*(1), 51-53.
- King, N. (2004). Using templates in the thematic analysis of text. In C. Cassell & G. Symon (Eds.), *Essential Guide to Qualitative Methods in Organizational Research*. Sage.
- Krone, N., Högler, W. & Barrett, T. G. (2009). Thoughts on paediatric diabetes care in the UK. *The British Journal of Diabetes & Vascular Disease*, 9(6), 259–267.
 https://doi.org/10.1177/1474651409350950
- Landers, S. E., Friedrich, E., & Miller, V. (2015). Self-efficacy mediates the associations of parental coercion and autonomy support to adherence in adolescents with type 1 diabetes. *Journal of Adolescent Health*, 52(2), 85-86. <u>https://doi.org/10.1016/j.jadohealth.2014.10.170</u>
- Lange, K., Jackson, C., & Deeb, L. (2009). Diabetes care in schools the disturbing facts. *Paediatric Diabetes*, *10*, 28-36. <u>https://doi.org/10.1111/j.1399-5448.2009.00613.x</u>
- Lawrence, S. E., Cummings, E. A., Pacaud, D., Lynk, A., Metzger, D. L. (2015). Managing type
 1 diabetes in school: Recommendations for policy and practice. *Paediatr Child Health*, 20(1),
 35-44. <u>https://doi.org/10.1093/pch/20.1.35</u>

- Lewis, D. W., Powers, P. A., Goodenough, M. F., & Poth, M. A. (2003). Inadequacy of in-school support for diabetic children. *Diabetes Technology & Therapeutics*, 5(1), 45-51. <u>https://doi.org/10.1089/152091503763816463</u>
- Macartney, B. (2012). Protecting the rights of disabled learners and their families to quality, inclusive early childhood education. *Children's Magazine*, 63-66.
- MacMillan, F., Kirk, A., Mutrie, N., Moola, F., & Robertson, K. (2014). Supporting participation in physical education at school in youth with type 1 diabetes. *European Physical Education Review*, 21(1), 3–30. <u>https://doi.org/10.1177/1356336x14534367</u>
- Marshall, M. (2017). Supporting young children with type 1 diabetes in primary schools in the north of England. *Journal of Diabetes Nursing*, *21*(6), 217-222.
- Marshall, M., Gidman, W., & Callery, P. (2013). Supporting the care of children with diabetes in school: A qualitative study of nurses in the UK. *Diabetic Medicine*, 30(7), 871-877. <u>https://doi.org/10.1111/dme.12154</u>
- Marx, T. A., Hart, J. L., Nelson, L., Love, J., Baxter, C. M., Gartin, B., & Schaefer Whitby, P. J. (2014). Guiding IEP teams on meeting the least restrictive environment mandate. *Intervention in School and Clinic*, 50(1), 45–

50. <u>https://doi.org/10.1177/1053451214532345</u>

- Maxwell, J. A. (2005). Qualitative research design. Sage.
- Melton, D., & Henderson, J. (2007). Children with diabetes: Satisfaction with school support,
 illness perceptions and HbA1c levels. *Journal of Developmental and Physical Disabilities*,
 20, 101-114. https://doi.org/10.1007/s10882-007-9082-4
- Miller, C. (2019). School nurse numbers drop by 30% since 2010, says RCN. *Nursing Children and Young People*, *31*(5), 6-6. <u>https://doi.org/10.7748/ncyp.31.5.6. s2</u>
- National Health Service (NHS). (2017). A London guide for teachers and parents of children and young people with diabetes: pre-school, early years, primary and secondary schools.

https://www.london.gov.uk/what-we-do/health/healthy-schools-

london/awards/sites/default/files/2CYP%20diabetes%20guide_proofed.pdf

- Northern Ireland Executive. (1995). *Disability discrimination act*. Retrieved November 28, 2021 from <u>https://www.legislation.gov.uk/ukpga/1995/50/contents</u>
- Northern Ireland Executive. (2005). *The special educational needs and disability (Northern Ireland) order*. Retrieved November 28, 2021 from

https://www.legislation.gov.uk/nisi/2005/1117/contents

- Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, 16(1), 1–13. <u>https://doi.org/10.1177/1609406917733847</u>
- Papatheodorou, K., Banach, M., Bekiari, E., Rizzo, M., & Edmonds, M. (2017). Complications of diabetes 2017. *Journal of Diabetes Research*, 2018. https://doi.org/10.1155/2018/3086167
- Scottish Government. (1978). *National Health Service (NHS) Scotland act*. Retrieved November 28, 2021 from https://www.legislation.gov.uk/ukpga/1978/29/contents
- Scottish Government. (1991). *Functions of health boards (Scotland) order*. Retrieved November 28, 2021 from https://www.legislation.gov.uk/uksi/1991/570/contents/made
- Scottish Government. (2000). *The standards in Scotland's schools (Scotland) act 2000*. Retrieved November 28, 2021 from https://www.legislation.gov.uk/asp/2000/6/contents
- Scottish Government. (2003). Education (disability strategies and pupils' educational records (Scotland) act. Retrieved November 28, 2021 from

https://www.legislation.gov.uk/asp/2002/12/contents

- Scottish Government. (2004). *The education (additional support for learning) (Scotland) act*. Online at https://www.legislation.gov.uk/asp/2004/4/contents
- Scottish Government. (2006). *Getting it right for every child (GIRFEC)*. Retrieved November 28, 2021 from <u>https://www.gov.scot/policies/girfec/</u>

- Scottish Government. (2009). Curriculum for excellence: Health and wellbeing: Experiences and outcomes. Retrieved November 28, 2021 from https://education.gov.scot/Documents/health-and-wellbeing-eo.pdf
- Scottish Government. (2014). *The Children and young people (Scotland) act*. Retrieved November 28, 2021 from https://www.legislation.gov.uk/asp/2014/8/contents/enacted
- Snyder, H. (2019). Literature review as a research methodology: An overview and guidelines. Journal of Business Research, 104, 333-339. <u>https://doi.org/10.1016/j.jbusres.2019.07.039</u>

Telford, F. A. (2017). Childhood diabetes. InnovAiT, 10(12), 713-720.

https://doi.org/10.1177/1755738017731461

- The Diabetes Control and Complications Trial Research Group (DCCT). (1993). The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin dependent diabetes mellitus. *New England Journal of Medicine*. 329(14), 977–986. <u>https://doi.org/10.1056/NEJM199309303291401</u>
- The United Nations Educational, Scientific and Cultural Organization (UNESCO). (1994). *The Salamanca statement and framework for action on special education needs*, Salamanca: United Nations Educational, Scientific and Cultural Organization.

http://www.unesco.org/education/pdf/SALAMA_E.PDF

- The United Nations Educational, Scientific and Cultural Organization (UNESCO). (2017). A guide for ensuring inclusion and equity in education. Paris. https://unesdoc.unesco.org/ark:/48223/pf0000248254
- The Welsh Government. (2010). Access to education and support for children and young people with medical needs. <u>https://gov.wales/sites/default/files/publications/2018-12/supporting-learners-with-healthcare-needs.pdf</u>
- Torgerson, C., & Light, K. (2012). Systematic reviews. In J. Arthur, M. Waring, R. Coe & L. Hedges, (Eds), *Research Methods and Methodologies in Education*. Sage.

- UK Government. (2022). *Children with special educational needs and disabilities (SEND)*. https://www.gov.uk/children-with-special-educational-needs/extra-SEN-help
- UK Government. (1989). Children's act. https://www.legislation.gov.uk/ukpga/1989/41/contents
- UK Government. (2002). The education act. https://www.legislation.gov.uk/ukpga/2002/32/contents
- UK Government. (2004). Children's act. https://www.legislation.gov.uk/ukpga/2004/31/contents
- UK Government. (2006). NHS Act. https://www.legislation.gov.uk/ukpga/2006/41/contents
- UK Government. (2010). The equality act. https://www.legislation.gov.uk/ukpga/2010/15/contents
- UK Government. (2014). Child and families act.

https://www.legislation.gov.uk/ukpga/2014/6/contents/enacted

- United Nations. (2006). Convention on the rights of persons with disabilities. https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf
- United Nations Children's Fund. (1989). UN convention on the rights of the child. Geneva: Office of the High Commissioner for Human Rights. <u>https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child</u>
- Van Der Knaap, L. M., Leeuw, F., Bogaerts, S., & Niissen, L. (2008). Combining Campbell standard and the realist evaluation approach: The best of two worlds? *American Journal of Evaluation*, 29(1), 48–57. https://doi.org/10.1177/1098214007313024
- Wagner, J., & James, A. (2006). A pilot study of school counsellor's preparedness to serve students with diabetes: Relationship to self-reported diabetes training. *Journal of School Health*, 76(7), 387-392). <u>https://doi.org/10.1111/j.1746-1561.2006.00130.x</u>
- Welsh Government. (2021). *The additional learning needs code for Wales 2021*. https://www.gov.wales/additional-learning-needs-code

Appendix A: Contents of an Individual Healthcare Plan

Aspect of Plan	Information to be Included
General learner information	The learner's name, date of birth, known allergies etc.
Identified stakeholders and roles	The learner, parents/guardians, school staff, healthcare professionals alongside specified duties and responsibilities.
Contact details	Contact information for relevant stakeholders and agreed methods of communication, e.g., email, telephone.
Equipment and supplies	A list of relevant equipment e.g., glucometer and supplies e.g., emergency box, Go Bag, Glucogel.
Self-management strategies	Reiterated duties of the learner, if appropriate, e.g., carrying out blood glucose checks with supervision.
Blood glucose monitoring	Methods used (glucometer/CGM), frequency, circumstances, equipment needed, instructions (if necessary).
Insulin administration	Delivery system and type e.g., Novorapid injection, regime and ratios, storage of insulin.
Meals and snacks	Carbohydrate levels of commonly consumed foods, food timetable.
Hypoglycaemia	Symptoms, blood glucose levels indicating hypoglycaemia, step by step treatment plan, instructions for glucagon delivery.
Hyperglycaemia	Symptoms, blood glucose levels indicating hyperglycaemia, step by step treatment plan, ketone checking, bolus details.
Considerations for Physical Education [P.E.]	P.E. timetable, additional blood glucose checks before and after.
Locations	Locations stated for the storage of supplies and if the learner desires a private room for treatment.
Absences	Details of policy and arrangements for absences due to diabetes-related appointments.
Examination considerations	Additional time (if required), permission to have emergency supplies and equipment.
Activities outside of school	Additional arrangements extra-curricular activities, including field trips e.g., additional supplies and supervision.
Additional support	Details of additional supports (if required) for the learner's educational, emotional and social needs.
Risk Assessments	A copy of the personal risk assessment should be reviewed and agreed to by all stakeholders.
Emergency situations	Step by step care plan and emergency services contact details.
Date of review	Stated and agreed upon by all stakeholders. A copy of the plan supplied to each stakeholder.
(ADA, 2013; ADCES, 2016; DfE, 2015; Edwards et a	l., 2014; NHS, 2017)

Appendix B: Sticker Communication System

	How Pupil X is feeling today (pupil- chosen sticker)	Tick if there was a hypoglycaemic episode	Tick if there was a hyperglycaemic episode	Any areas of concern.
Monday		\checkmark		Pupíl X dídn't eat their apple today.
Tuesday				
Wednesday		\checkmark		Pupíl X felt 'sleepy' duríng P.E. today.
Thursday				
Friday			\checkmark	Pupil X felt 'thirsty' today during a hyper episode.

Appendix C: Weekly Parental Duty Checklist

lf t co	If there are any changes in Pupil X's regime and routine, please leave details below and contact the school to discuss.						
Tic	k where appropriate.						
۱h	I have checked the following equipment and supplies are present and are in good condition.						
0	 Glucometer plus spare batteries. 						
0	• CGM (if relevant).						
0	Testing strips plus spare lancets.						
0	 Ketone strips. 						
0	Insulin pen plus sharps.						
0	Insulin pump – reservoir, spare tubing/catheter and infusion set.						
0	Emergency supplies – Glucagon, Glucogel.						
0	Go Bag/Emergency Box supplies – Glucose tabs, fruit juice, snacks.						
0	 I have reviewed and returned the diabetic diary. 						
0	 I have ensured that emergency contact details are up to date. 						
Sig	gned: Date:						

Appendix D: Emergency Plan Sample



Do not leave the student unattended.

Mild Hypo: Child X is conscious and able to co-operate and swallow independently.

Step 1: Immediately give 15g of fast acting carbohydrate:

One of:

- 150mls of fruit juice
- 150mls of full-sugar drinks e.g., Coca Cola Regular, 7up
- 3-5 glucose tablets
- 3-4 sweets e.g., jelly babies

Step 2: Wait 10 minutes.

Step 3: Repeat blood glucose test. If still below 4.0mmol, repeat step 1. If above 4.0mmol, move to step 4.

Step 4: Follow treatment with a slow acting carbohydrate snack which is one of the following:

- Portion of fruit
- Cereal bar
- Or a meal if it is due.
- Step 5: Record event in diary.

Moderate Hypo: Child X is unable to co-operate but can swallow and is conscious.

Step 1: Use one tube of Glucogel

twist top to remove, insert the tip of the tub
 into Child X's mouth between gum and cheek,
 slowly squeeze until all gel is dispensed,
 massage the outer cheek gently

Step 2: <u>Wait 5-10 minutes and re-check blood glucose</u>.

Step 3: If blood glucose is less than 4.0mmol, repeat gel.

Step 4: <u>Follow</u> treatment with a slow acting carbohydrate snack which is <u>one</u> of the following:

- Portion of fruit
- Cereal bar
- Or a meal if it is due.

Severe Hypo: Child X is unconscious.

Step 1: Put Child X is the <u>recovery position</u> and check that they are breathing.

Step 2: Call an ambulance at <u>999 or 112</u> and state that they have type 1 diabetes and their current blood glucose level.

Step 3: Follow instructions from the emergency services team.

Step 4: If a <u>trained member</u> of staff is on-site to deliver the Glucagon injection:

 0.5mg (half dose) for children less than 8 years old or less than 25kg and 1mg does if over 8 years or more than 25kg.

Step 5: Contact parents/guardians.

Step 6: When awake, follow steps outlined in Mild or Moderate as appropriate.

Step 7: On recovery, Child X should be taken home by parents/guardians and the event should be **recorded**.

Emergency plan for hyperglycaemia for Child X in Class Y.



Student name:	
Date of birth:	Photo
Allergies:	
Next of kin:	

When to check blood glucose level:

- Before meals.
- Any time hypo is suspected or student feels unwell.
- Before and after activity.
- <u>Refer to individual healthcare plan.</u>

When to administer insulin:

- After blood glucose check and before meals.
- Hyperglycaemic events.
- Refer to individual healthcare plan.

Designated	care	co-ord	linator(s	s) on trip:	
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Parent/Guardian:



Healthcare Contacts:

School nurse:

PDSN:

GP:

Tick relevant treatment details:

 \circ CGM

- Insulin injections
- Insulin pump

Designated location for testing and treatment:

Location to store equipment and supplies:

Location to dispose of used equipment:



Appendix F: Rufus the Diabetic Teddy (JDRF, 2021b: online)



Snippet of book relating to the self-management of hypoglycaemia.

