

Cohort monitoring of persons with diabetes mellitus in a primary healthcare clinic for Palestine refugees in Jordan

Ali Khader¹, Loai Farajallah¹, Yousef Shahin¹, Majed Hababeh¹, Ishtaiwi Abu-Zayed², Arata Kochi³, Anthony D. Harries^{4,5}, Rony Zachariah⁶, Anil Kapur⁷, Wendy Venter¹ and Akihiro Seita¹

1 United Nations Relief and Works Agency for Palestine Refugees in the Near East, Amman, Jordan

2 Field Health Programme, United Nations Relief and Works Agency, Amman, Jordan

3 Tokyo University Medical School, Tokyo, Japan

4 International Union Against Tuberculosis and Lung Disease, Paris, France

5 London School of Hygiene and Tropical Medicine, London, UK

6 Medecins Sans Frontieres, Medical Department, Operational Research Unit, Brussels Operational Center, Luxembourg, Luxembourg

7 World Diabetes Foundation, Gentofte, Denmark

Abstract

OBJECTIVE To illustrate the method of cohort reporting of persons with diabetes mellitus (DM) in a primary healthcare clinic in Amman, Jordan, serving Palestine refugees with the aim of improving quality of DM care services.

METHOD A descriptive study using quarterly and cumulative case findings, as well as cumulative and 12-month analyses of cohort outcomes collected through E-Health in UNRWA Nuzha Primary Health Care Clinic.

RESULTS There were 55 newly registered patients with DM in quarter 1, 2012, and a total of 2851 patients with DM ever registered on E-Health because this was established in 2009. By 31 March 2012, 70% of 2851 patients were alive in care, 18% had failed to present to a healthcare worker in the last 3 months and the remainder had died, transferred out or were lost to follow-up. Cumulative and 12-month cohort outcome analysis indicated deficiencies in several components of clinical care: measurement of blood pressure, annual assessments for foot care and blood tests for glucose, cholesterol and renal function. 10–20% of patients with DM in the different cohorts had serious late complications such as blindness, stroke, cardiovascular disease and amputations.

CONCLUSION Cohort analysis provides data about incidence and prevalence of DM at the clinic level, clinical management performance and prevalence of serious morbidity. It needs to be more widely applied for the monitoring and management of non-communicable chronic diseases.

keywords diabetes mellitus, Palestine refugees, Jordan, cohort reports

Introduction

The global burden of diabetes mellitus (DM) is immense and increasing. In 2011, there were an estimated 366 million people living globally with DM, of whom 183 million (50%) were undiagnosed (International Diabetes Federation 2011). Complications due to DM are a major cause of disability and diminished quality of life; in 2011 an estimated 4.6 million people died of DM. Driven by changes in socio-economic conditions, urbanisation, Western-style diets and physical inactivity, the global prevalence of DM is expected to reach 552 million by 2030.

In many parts of the world, unstructured and unmonitored clinical care of DM is the norm, and there is little regular or reliable information from health facilities about

DM incidence and prevalence, treatment outcomes, associated morbidity or mortality. We have argued previously that this unsatisfactory situation can be rectified and that the 'cohort' recording and reporting systems adapted from the DOTS (directly observed therapy, short course) framework for tuberculosis control can be used to monitor chronic disease such as DM (Harries *et al.* 2008). In Malawi, the DOTS system has been successfully used for monitoring the treatment of HIV/AIDS (Harries *et al.* 2009a) and to monitor case burden and treatment outcomes in patients with DM in a central referral hospital (Allain *et al.* 2011).

The United Nations Relief and Works Agency for Palestine Refugees (UNRWA) has been working in the Near East for 62 years, and provides health, education and

A. Khader *et al.* Cohort reporting for patients with diabetes mellitus

social services for about 5 million Palestine refugees in Jordan, Lebanon, Syria, the West Bank and Gaza Strip (UNRWA 2011). It currently delivers health services through 138 primary healthcare (PHC) centres and one hospital in the West Bank, and the main focus of its health work is the provision of general medical care, maternal and child health care and diagnosis and treatment of non-communicable diseases, particularly DM and hypertension. Prevalence of DM and hypertension among the served population aged 40 years and above attending the health facilities is 11.4% and 17.5%, respectively, and in 2011 almost 211 000 people with DM and/or hypertension were being cared for at UNRWA clinics in the region (UNRWA 2011).

In one of the primary healthcare clinics, Nuzha PHC, in Jordan, we have previously described the use of cohort reporting in Palestine refugees with hypertension (Khader *et al.* 2012). From the same clinic, we now describe the use of quarterly reporting for cases and treatment outcomes to assess the burden of disease and management of patients with DM, and we discuss how these data can inform and improve DM care services in the clinic.

Methods

Design and Setting

This is a retrospective descriptive study of the cohort reporting framework to monitor burden of disease and management of persons with DM at Nuzha PHC Clinic. The study was conducted in Nuzha PHC Clinic in Amman (Khader *et al.* 2012). In Jordan, a country of 6 million people, there are 2 million registered Palestine refugees, of whom 17% live inside 10 official camps. UNRWA has 24 PHC clinics in Jordan. Through these clinics, the organisation serves all registered Palestine refugees in the country, of whom 53% access UNRWA services. Nuzha PHC clinic is located outside of the camps and serves a catchment population of approximately 55 000 refugees. The refugees in the catchment area are Arab-Palestinians with Jordanian nationality, the refugees and descendants having lost their normal place of residence in Palestine as a result of the 1948 Arab-Israeli conflict. The refugees are usually of middle- and low-income class, predominately professionals, employees, skilled and unskilled labourers and with high unemployment rates in women. There is good food security with generally a balanced Mediterranean diet rich in cereals, vegetables, legumes and fruits. However, while macro-nutrition deficiency is rare, micronutrient deficiency is common among women and children. Rates of cigarette smoking are high and regular physical activity is uncommon. The population is generally young with a low

rate of illiteracy, and regular attendance for preventive health care such as vaccination uptake, antenatal visits, post-natal care and health screening programmes is the norm. Major communicable diseases (e.g., TB and HIV/AIDS) are under control, but with life expectancy becoming longer, there is an increasing incidence of non-communicable diseases, especially DM and hypertension. The catchment population attends Nuzha PHC Clinic, which is staffed by four doctors and a variable number of nurses and support staff. All screening, diagnosis and treatment services at the clinic are provided free of charge.

Persons with DM and their management: Palestine refugees who attend the clinic are screened annually for DM and 6-monthly for hypertension if they are 40 years or older, if they are judged to be at risk for non-communicable diseases and if they are pre-conception or pregnant women. DM screening is performed by measuring random blood glucose (RBG) upon attendance at the clinic, and if this is ≥ 126 mg/dl, the diagnosis is confirmed/refuted within a week through two fasting blood glucose (FBG) measurements, both of which must be ≥ 126 mg/dl for a confirmed diagnosis of DM (WHO 2006; UNRWA 2009). Those with an FBG between 110 and 125 mg/dl are further screened for DM using an oral glucose tolerance test.

Persons diagnosed with DM are clinically assessed for complications and co-morbidities such as hypertension (defined as a blood pressure of 140/90 mmHg or above), and these along with demographic and clinical information are recorded in a patient registration file and the E-Health system. Patients are categorised into three main groups DM Type 1, DM Type 2 and DM + Hypertension and further classified as new or previously diagnosed and diagnosis made within or outside of the UNRWA system. A record is also made about whether the patient has been transferred in from another UNRWA clinic.

Patients are managed according to a standard algorithm with diet and lifestyle advice, oral hypoglycaemic drugs (glibenclamide, glicazide and metformin) and insulin and are assessed as having controlled or uncontrolled DM, based on measurements of 2-h post-prandial blood glucose (PPBG). Patients with uncontrolled DM are seen weekly or monthly until their 2-h PPBG drops below 180 mg/dl. The follow-up schedule for patients with controlled DM is to see them at the clinic every 3 months, and during this clinic visit, the patients are assessed as follows: body mass index, urine for glucose and albumin, measurement of 2-h PPBG and blood pressure and the presence/absence of late complications (defined as blindness, end-stage renal failure, myocardial infarction, congestive cardiac failure, stroke and above-ankle amputation). Once a year, all patients DM are also expected to have a foot examination,

A. Khader *et al.* Cohort reporting for patients with diabetes mellitus

a referral to the ophthalmologist and blood tests for total cholesterol and serum creatinine.

In 2009, UNRWA started an electronic health record system (E-Health), which is operational in 6 PHC clinics in Jordan, including Nuzha PHC Clinic. The electronic health system is used to monitor non-communicable diseases, maternal health, child health and general outpatients (Khader *et al.* 2012). In brief, all clinical information is recorded using electronic keyboard-operated work stations that are set up in every clinic room, including the pharmacy and laboratory, and these are connected to a central server that stores the data. The healthcare workers in the clinic use the password-protected computers to enter patient information during clinical encounters at the point-of-care. Patients are all given health cards and identification numbers, and these are used to trace the electronic data. The E-Health system is a tool to facilitate good clinical care and also allows cohort data to be collected and analysed.

Patient population

All patients who were registered and entered into the E-Health system with DM from 1 October 2009 to 31 March 2012 in Nuzha PHC Clinic were included in the study.

Source of data, variables, cohort reporting formats and analysis

The data for the patients were obtained from the Clinic E-Health system. Data variables for the cohorts included age, sex, category of DM including whether there was associated hypertension, new or previous diagnosis of DM, place of diagnosis, whether the patient has been

transferred in from another UNRWA clinic, current outcome status as of 31 March 2012, current management, quarterly blood pressure measurements, whether quarterly or annual screening tests and blood tests had been conducted along with their results and the presence or absence of late complications. The definitions of variables for the management of patients and for the cohort reports are shown in Table 1 and are similar to what has been described previously for hypertension (Khader *et al.* 2012).

For this study, data were collected, aggregated and presented in four cohort reports: (i) Quarterly Registration (patients with DM newly registered between 1 January 2012 and 31 March 2012); (ii) Cumulative Registration (total number of patients with DM ever registered up to 31 March 2012, including the new quarterly registrations); (iii) Cumulative Outcomes (outcomes of all patients with DM ever registered up to 31 March 2012, with the outcomes censored on March 31st); and (iv) 12-month outcome analysis (the outcomes of patients with DM who were newly registered in quarter 1, 2011, with data censored on 31 March 2012). Comparisons between groups were made using the chi-squared test with a 5% level of significance.

Ethical approval

The data for the study included retrospectively collected routine patient information on DM. Data were aggregated for the cohort reporting, and no individual patient identifiers were used. Approval for the study was obtained from UNRWA Headquarters, and ethical approval for reporting on the study was obtained from the Union Ethics Advisory Group.

Table 1 Definitions for the management and recording of patients with diabetes mellitus (DM) for the cohort reports

Quarterly and cumulative registrations	
New diagnosis	Date of registration occurs within 4 weeks of date of diagnosis
Previous diagnosis	Date of registration occurs 4 weeks or later from date of diagnosis
Transferred in	Previously registered in another UNRWA clinic and now transferred to the current clinic
Hypertension	Blood pressure more than 140/90 mmHg on two or more occasions
Cumulative treatment outcomes	
Remaining in care	Alive and in care and seen by a doctor or nurse during quarter 1, 2012
Dead	Died at any time from any cause
Transferred out	Permanently transferred out from the clinic to another clinic
No quarterly attendance	Not seen in the clinic in quarter 1, 2012, by a doctor or a nurse
Lost to follow-up	No quarterly attendances on four consecutive occasions at the clinic
12-month survival analysis	
Diabetes in control	2 of the last 3 post-prandial blood glucose measurements (PPBG) \leq 180 mg/dl
Diabetes out of control	2 of the last 3 post-prandial blood glucose measurements (PPBG) $>$ 180 mg/dl
Diabetes undetermined	2 or more post-prandial blood glucose (PPBG) measurements not carried out in last 3 visits and $<$ 3 PPBG readings in a year, at the time of assessment

A. Khader *et al.* Cohort reporting for patients with diabetes mellitus**Table 2** Quarterly Cohort Registration of patients with diabetes mellitus (DM) (January to March 2012)

Patient characteristics	Number	%
Patients with DM newly registered in the quarter	55	
Gender		
Male	31	56
Female	24	44
Age Group in years: at time of registration		
<20	2	4
20–39	6	11
40–59	32	58
60 and above	15	27
Category of Disease: at the time of registration		
DM Type 1 alone	2	4
DM Type 2 alone	16	29
DM Type 2 and Hypertension	37	67
Diagnosis		
New	22	40
Previous	33	60
Place of Diagnosis		
Inside UNRWA	22	40
Outside UNRWA	33	60
Transferred in	0	0

DM, diabetes mellitus; UNRWA, United Nations Relief and Works Agency for Palestine Refugees in the Near East.

Results

The four cohort analyses and the results from Nuzha PHC Clinic are shown in Tables 2–5. Table 2 shows that 85% of new registrations were 40 years or older, 40% were new diagnoses and more than two-thirds of patients with DM already had hypertension at the time of registration. Of the 2851 patients with DM ever registered at Nuzha PHC because E-Health was set up, the majority of patients were at least 40 years old, similar to new registrations, but there were some significant differences in that there were more patients with a known diagnosis of DM and more patients diagnosed within the UNRWA system ($P < 0.05$) (Table 3).

The outcomes of the whole cumulative cohort with data censored on 31 March 2012 (Table 4) reveal two valuable programme performance indicators for the last quarter: 42% had post-prandial blood glucose measured and 50% had normal blood glucose. Of those diagnosed with hypertension, 63% had blood pressure measured and 75% had a normal reading.

Finally, a quarterly cohort outcome analysis on patients with DM newly registered 1 year previously (January to March 2011) and assessed in quarter 1, 2012 (Table 5) show that in terms of recommended annual assessments,

Table 3 Cumulative Cohort Registration Cohort of patients with diabetes mellitus (DM) (patients ever registered up to 31st March, 2012)

Patient characteristics	Number	%
All patients with DM ever registered, including the newly registered, up to 31 March 2012	2851	
Gender		
Male	1314	46
Female	1537	54
Age Group in years: at time of registration		
<20	43	2
20–39	263	9
40–59	1670	59
60 and above	875	30
Category of Disease: at time of registration		
DM Type 1 alone	70	2.5
DM Type 2 alone	585	20.5
DM Type 2 and Hypertension	2196	77
Diagnosis		
New	777	27
Previous	2074	73
Place of Diagnosis		
Inside UNRWA	2126	75
Outside UNRWA	725	25
Transferred in	95	3

DM, diabetes mellitus; UNRWA, United Nations Relief and Works Agency for Palestine Refugees in the Near East.

while the blood tests for cholesterol and creatinine were well performed, very few patients had their foot care examinations and there were no data on whether ophthalmic examinations had been carried out.

Discussion

This is the first report from a primary healthcare clinic setting to show how the DOTS cohort monitoring system can be adapted and used to monitor and report on persons with DM in Jordan. As is the case in patients who have hypertension (Khader *et al.* 2012), this information is useful for the UNRWA diabetes care services and can provide information that is relevant to disease management, assessing programme performance, patient outcomes and long-term healthcare impact (Table 6).

The report on patients newly registered in the DM clinic during a quarter provides informative data on 'new incident cases presenting to the clinic', and this information can be compared with the data on the cumulative number of registered patients who have presented at the clinic, allowing healthcare providers to assess over time whether patient characteristics of clinic attenders is changing. Ongoing community awareness programmes are trying to

A. Khader *et al.* Cohort reporting for patients with diabetes mellitus**Table 4** Cumulative Cohort Outcomes of patients with diabetes mellitus (DM) (patients ever registered up to 31st March, 2012)

Patient characteristics and treatment outcomes	Number	%
All patients with DM ever registered, including the newly registered, up to 31 March 2012	2851	
Principal outcome as determined on 31 March 2012		
Remaining in care	1981	70
Dead	69	2
Transferred out	54	2
No attendance in quarter 1 (January to March 2012) at the clinic	506	18
Lost to follow-up	241	8
Of patients remaining in care: current treatment	1981	
Not recorded	16	1
Diet only	116	6
Oral hypoglycaemic drugs	1326	66
Insulin	191	10
Insulin plus oral hypoglycaemic drugs	332	17
Of patients remaining in care: measurements in quarter 1, 2012	1981	
Post-prandial blood glucose (PPBG) measured:		
Post-prandial blood glucose (PPBG) \leq 180 mg/dl	415	50*
Associated diagnosis of Hypertension	1563	79
Blood pressure measured	983	63†
Blood pressure <140/90	735	75‡
Of patients remaining in care: late complications	1981	
Patients with one or more late complications	347	18
Patients who are blind	31	2
Patients with end-stage renal disease	5	<1
Patients with myocardial infarction	171	9
Patients with congestive cardiac failure	80	4
Patients with stroke	104	5
Patients with above-ankle amputation	3	<1

DM, diabetes mellitus.

*% of those who had post-prandial blood glucose measured.

†% of those with an associated diagnosis of hypertension.

‡% of those who had blood pressure measured.

ensure much earlier diagnosis and promote healthy life styles and thus patients may be less affected by complications at the time of diagnosis and registration. The frequency of new quarterly cases at the clinic and co-morbidity at the time of registration and tracked over time may indicate the success or otherwise of these community-based prevention strategies.

The cumulative number of patients alive and remaining in care at set moments in time is another vital piece of

strategic information that indicates prevalent disease at the clinic (Harries *et al.* 2009b), and this can help clinic staff to make rational logistic plans and forecasts for consumables and drugs based on accurate numbers of patients in care. 'Lost to follow-up' status means no attendance at the clinic for 12 consecutive months, and operational research could usefully be performed to determine why patients have failed to attend. This type of analysis may also identify barriers and thereby solutions to service delivery.

Of more relevance to immediate management is the number of patients who failed to attend the clinic in the quarter. E-Health could be used to identify and flag these patients, and, with the use of mobile phone technology, attempts could be made to ensure the patients attend the next quarter so that continuity of care and uninterrupted drug intake are maintained. Mobile phone technology has been used successfully in low- and middle-income countries to improve the long-term follow-up of HIV-infected patients on antiretroviral therapy (Chi & Stringer 2010; Lester *et al.* 2010), and operational research could be performed to assess whether the same success can be achieved in the management of non-communicable diseases such as diabetes, especially in reducing losses to follow-up and failure to attend clinic appointments.

Of patients who did attend the clinic in the last quarter, a sizeable proportion failed to have postprandial blood glucose measurements, and in those with known hypertension, a proportion failed to have their blood pressure recorded. At the moment, it is uncertain whether these apparent clinical management failures are errors of recording or non-adherence to UNRWA guidelines (UNRWA 2009), but on both counts, the two pieces of data indicate a need for improved performance of either E-Health and/or patient management. If related to patient management, consideration needs to be given to simpler ways of assessing blood glucose control. For example, measurement of glycosylated haemoglobin (HbA_{1c}), although more expensive than measurement of post-prandial blood glucose, is quicker, does not need repeat visits and provides a better index of blood glucose levels over a period of 2–3 months (Kumar *et al.* 2010; WHO 2011). Ideally, every patient should have these measurements of blood glucose and blood pressure at least once every quarter, and all attempts should be made to ensure the parameters are controlled through medication and adherence to better lifestyles. Chronic disease requires structured care, but this usually occurs in the setting of high patient loads. In the future, it will be important to identify what routine tasks can be carried out by non-medical health professionals and what needs to be referred to specialist attention.

A. Khader *et al.* Cohort reporting for patients with diabetes mellitus**Table 5** 12–15 month Cohort Outcome Analysis of patients with diabetes mellitus (DM)*

Patient characteristics and outcomes	Number	%
Patients with DM newly registered in Quarter 1 (Jan to Mar) 2011	117	
Principal outcome as determined on 31 March 2012		
Remaining in care	71	61
Dead	0	0
Transferred out	3	3
No quarterly attendance at the clinic in quarter 1, 2012	43	36
Lost to follow-up	0	0
Of those remaining in care: current management	71	
Not recorded	0	
Diet only	4	6
Oral hypoglycaemic drugs	54	76
Insulin	8	11
Insulin plus oral hypoglycaemic drugs	5	7
Of those remaining in care: DM control	71	
Diabetes in control	41	58
Diabetes out of control	28	39
Diabetes control undetermined	2	3
Of those remaining in care: BP in current quarter	71	
With an associated diagnosis of hypertension	51	72
Of those blood pressure measured	37	73
Of those blood pressure <140/90	27	73
Of those remaining in care: Annual Assessment	71	
Foot care examination carried out during the 12 months	2	3
Referred to ophthalmologist during the 12 months	No data	No data
Blood total cholesterol measured at least once in 12 months	71	100
Of those, total cholesterol <200 mg/dl	51	72
Serum creatinine measured at least once in 12 months	70	99
Of those, serum creatinine <1.2 mg/dl	63	90
Of those remaining in care: late complications	71	
Patients with one or more late complications	7	10
Patients who are blind	0	0
Patients with end-stage renal disease	0	0
Patients with myocardial infarction	5	7
Patients with congestive cardiac failure	1	1
Patients with stroke	1	1
Patients with above-ankle amputation	0	0

*The cohort is patients newly registered with DM between 1 January 2011 and 31 March 2011 who are assessed for outcomes in March 2012 12–15 months later.
DM, diabetes mellitus; BP, blood pressure.

While the cumulative outcome report provides a useful cross-sectional snapshot of the clinic programme at a set point in time, it is limited by the fact that the time periods of the E-health registered patients range from years when patients were first diagnosed to a few days for the latest patients being registered just before the census date on 31 March, 2012. For this reason, the 12-month cohort outcome analysis provides a much better assessment of treatment outcomes, clinical management performance and quality of control for a smaller group of patients registered over a 3-month period, in this case 1 January 2011 to 31 March 2011, with outcomes assessed 12 months in the future. Although this is not strictly a 12-month outcome analysis as some patients are followed for 15 months, in the context of routine monitoring this is good enough to inform about programme performance and assessing whether interventions as specified in UNRWA guidelines are being carried out on a quarterly or an annual basis, what proportion of patients have their DM controlled and their cholesterol and creatinine in the normal range and, of those with hypertension, what proportion have their blood pressure under control. Furthermore, the number with late complications at 1 year after registration provides a baseline assessment from which to compare serious morbidity during longer-term follow-up.

UNRWA will collect these cohort data on a quarterly basis, with this type of routine analysis enabling the programme to look at whether programme performance and disease control in later cohorts are improving and long-term whether this makes a difference to the patients' health status. This approach is very similar to the quarterly cohort analysis conducted in Malawi for HIV/AIDS patients on antiretroviral therapy (Libamba *et al.* 2006). At each 12-month period, an annual cohort analysis can also be conducted with more detailed information being provided at the time.

E-Health is essential for enabling this type of cohort analysis to work. Using paper-based registers and cards to do manual calculation of cohorts and outcomes is time-consuming and takes health staff away from patient care. A real-time electronic system at the point-of-care greatly facilitates cohort analysis, and, although setting up such a system may appear to be a daunting proposition, it is sometimes easier to do this *de novo* in low- and middle-income countries than in more developed countries (Douglas *et al.* 2010; Allain *et al.* 2011). There is evidence that electronic systems can also lead to better individual patient care as the system prompts clinicians for complication screening and stores information on complications in an accessible format (Douglas *et al.* 2010). An electronic database also provides an infra-structural platform for audit and operational research, the

Table 6 Value of Cohort Report System for patients with DM in terms of service performance, quality of care and health status

	Measures of DM service performance	Outcome	Impact on health status
Quarterly cohort registration	Quarterly incidence of DM	Information on case detection Rational planning for drugs	Better access to diagnosis and care Uninterrupted drug supplies
Cumulative cohort registration	Prevalence of DM	Information on disease burden Rational planning for drugs	Attention to risk factors to reduce future disease burden Uninterrupted drug supplies
Cumulative cohort outcomes	% attendance in last quarter % lost to follow-up and died % PPBG carried out in last quarter % BP measured in last quarter	% complying with care % normal blood glucose % normal BP	Better diabetes control Prevent late complications
12-month cohort outcome analysis	% DM control determined % BP measured % Foot care examination performed % Referral to ophthalmologist % Assessment of cholesterol % Assessment of creatinine	% DM in control % Normal BP % with foot ulcers % with preventable eye disease or retinopathy needing laser therapy % needing statins % needing ACE inhibitors	Prevent late complications Prevent diabetic foot and amputations Prevent blindness Prevent cardiovascular disease Prevent renal failure Prevent strokes

DM, diabetes; BP, Blood Pressure; PPBG, post-prandial blood glucose; ACE inhibitors, angiotensin-converting-enzyme inhibitors.

cohort analysis prompting research questions that if answered can lead to an improvement of programme performance.

In conclusion, the use of cohort reporting is seen as a valuable monitoring tool for managing DM in Palestine refugees and provides useful, real-time data on the burden of DM and its management at the primary clinic level. The data sets can also serve as a useful source of information for operational research on the introduction of new medications, new diagnostic technologies and new models of healthcare delivery. UNRWA will expand cohort analysis to the other PHC clinics in Jordan that already have E-Health as well as expand E-Health to all PHC clinics in the country. The logistics of reporting from the clinic level and then at the national level will be worked out as this plan progresses. Cohort reporting and E-health obviously requires resources, but a 'data-rich, information-rich' programme should improve its performance leading to improved patient outcomes and better health status.

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A. Khader *et al.* **Cohort reporting for patients with diabetes mellitus**

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Corresponding Author Anthony D. Harries, Old Inn Cottage, Vears Lane, Colden Common, Winchester SO21 1TQ, UK.
Tel.: +44 (0) 1962 714 297; E-mail: adharries@theunion.org