A Review of
Adolescent Personal Health Cards:
Practice and Potential

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Abbreviations/Acronyms

ASRH	Adolescent sexual and reproductive health
CDC	Centers for Disease Control
CRS	Catholic Relief Services
DFID	Department for International Development (UK)
EMR	Electronic medical record
EPHR	Electronic personal health record
FHI	Family Health International
GAVI	Global Alliance for Vaccines and Immunizations
HPV	Human papilloma virus
IPPF	International Planned Parenthood Federation
IVB	Immunization, Vaccines and Biologicals
LMIC	Low and middle-income country
M-technologies	Mobile phone based technologies
MAMTA	Health Institute for Mother and Child
MCA	Maternal, Newborn, Child and Adolescent Health
PHR	Personal health record
PCHR	Personally controlled health record
SCF	Save the Children Fund
Swiss FOPH	Federal Office of Public Health, Switzerland
USAID	United States Agency for International Development

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Executive Summary

The expansion of immunization beyond infants into older age groups, including the introduction of HPV vaccine, provides opportunities to link vaccination programmes with adolescent health programmes more generally. In exploring these potential synergies it became clear that there was a need to review the use of adolescent health cards for the contribution that they might make.

A literature search for the period 2000 to 2012 did not identify any published articles focusing on adolescent personal health cards, although a number of publications were identified that dealt with other forms of recording health information about adolescents, including m-heath applications and electronic personal health records. However, since the majority of these were either not retained by the adolescents or were designed specifically to support treatment and care they were not included in the subsequent analysis.

In addition to the literature search, contact was made with over 50 organizations and recognized experts in the field of adolescent health (UN agencies, development partners, NGOs, and academics) to identify examples of adolescent personal health cards and obtain information about their use. This was supplemented by an Internet search.

Despite wide scale interest in the issue, only three of the people contacted were able to provide examples of adolescent personal health cards, none of which had been evaluated in terms of their use or usefulness. Again, a number of examples of electronic personal health records were identified through this process, but, with the exception of the use of mobile phones, these were mostly excluded from further analysis for the reasons mentioned above.

Lessons learned from child health (road-to-health) cards and home-based cards used for maternal health were also reviewed to identify lessons learned that might be applicable to the use of adolescent health cards.

Adolescent personal health cards may fill a number of functions: reminding people about appointments; monitoring health, at individual and population levels; providing information to adolescents, parents and service providers; improving care, facilitating referral and supporting transitioning; and even empowering adolescents. They may additionally have the potential to strengthen linkages and collaboration between different service providers and different sectors.

In view of adolescents' developing capacities and growing independence during the adolescent years it may be necessary to design adolescent personal health cards differently for early and later adolescence. The issue of confidentiality needs to be given adequate consideration, as do countries' overall plans for the use of health cards across the life course.

Apart from these broad generalizations, it was not possible to draw many conclusions from the present study, in view of the lack of published literature or

examples of cards being used, or of their use being evaluated. There are a number of lessons to be learned from the use of child health cards, however, including the need to be clear about the objectives of the cards, and the importance of educating and training parents, clients and health workers if they are to be used effectively.

Based on the findings of the review, recommendations are made in three areas:

1. First, to further explore and develop adolescent personal health cards within the context of vaccination programmes targeted to the adolescent age group, particularly in those situations where there is the intention to integrate other health interventions with the provision of vaccines;
2. Secondly, to assess the potential use of adolescent personal health cards more generally in relation to the provision of services for adolescents;
3. Finally, to explore the use of mobile phone and electronic media technologies to provide the functions of adolescent personal health cards.

1. Introduction

During the past two decades there has been growing attention paid to improving the capacity of health systems to meet the specific needs of adolescents, both in terms of health facilities[1] [2] and through school health services[3]. During this time a number of international consensus statements have highlighted the importance of increasing adolescent's access to health services[4] [5], and there has been a growing evidence base for effective approaches to increasing young people's use of services[6] in terms of training service providers[7] [8], making changes in health facilities[9] and generating demand and community support[10].

One aspect of health service provision for adolescents that has received relatively little attention is the use of the personal health cards that have been used in other population groups. Such cards have been used for children under five years of age[11], with the aim of having a simple, cheap, practical and effective means of promoting and monitoring children's health, contributing to the early detection and prevention of childhood illness, and supporting national systems for surveillance and programme monitoring. They have been used to provide information for parents and health workers on a range of issues including birth data, growth, immunization, neurological development and episodes of illness. Personal heath cards have also been used for pregnant women[12].

Personal health cards designed for adolescents might additionally play an important role in terms of specific interventions, such as male circumcision for HIV prevention, HIV counselling and testing (HCT), and a number of screening and treatment interventions being provided through school health services. They have the potential to contribute to such programmes by providing important details about adolescents' health and development, and contact with the health system, for their parents, for health workers and programme planners, and for adolescents themselves. For adolescents the benefits are likely to be two-fold: on the one hand providing information on their health and development, and on the

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[1] WHO (2002): *Adolescent Friendly Health Services – an agenda for change*
[2] http://www.pathfinder.org/publications-tools/
[3] Bundy, D (2011): *Rethinking school health: a key component of education for all*. World Bank.
[4] http://www.un.org/ecosocdev/geninfo/populatin/icpd.htm
[5] data.unaids.org/publications/irc-pub03/aidsdeclaration_en.pdf
[6] Dick B, Ferguson J, Chandra-Moduli V et al (2006): Evidence for Interventions to Increase Young People's Use of Services in Developing Countries, WHO TRS 938
[7] WHO (2006): Orientation Programme on Adolescent Health for Health Care Providers. http://www.who.int/maternal_child_adolescent/documents/9241591269/en/index.html
[8] ICRW (2012): *A Study to Evaluate the Effectiveness of WHO Tools*, http://www.icrw.org/publications/study-evaluate-effectiveness-who-tools
[9] WHO (2012): *Making health services adolescent friendly – developing national quality standards for adolescent-friendly health services*
[10] WHO (2009): *Generating demand and community support for sexual and reproductive health services for young people – a review of the literature and programmes*
[11] Crisp NG and Donald PR (1987): *The "Road to Health Card" and immunization records*, SAMJ, 72, 331-333
[12] Turner KE and Fuller S (2011): *Patient-held maternal and/or child health records: meeting the information needs of patients and healthcare providers in developing countries*, Online Journal of Public Health Informatics, **3**, 2

other prompting the use of health interventions that are being delivered, including relevant screening and other services.

With increasing attention being paid both to vaccination programmes for the adolescent age group [13], and also to the potential for additional interventions to be integrated with the administration of these vaccines[14], it is likely that there will be a need for recording, reminding, monitoring and strengthening linkages and referral between different providers responsible for adolescent's health and development, including between health facilities and schools (particularly where school-based vaccination strategies are adopted). Adolescent personal health cards could potentially meet some of these requirements.

The present study was designed to explore experiences with the use of adolescent personal health cards, with a view to strengthening and developing their use both in vaccination programmes and also in the provision of health services for adolescents more generally.

2. Objectives and Methodology

2.1. Objectives

The objectives of the review were to:

1. Review the available literature on adolescent health cards/personal health records;
2. Identify specific issues that need to be taken into consideration in relation to adolescent health cards/personal health records for adolescents (e.g. confidentiality, use of new information technology);
3. Synthesize key elements of adolescent heath cards/personal health records that are currently in use, both in terms of their content and how they are used;
4. Identify examples of good practice in the use of adolescent health cards/personal health records;
5. Synthesize lessons learned from the use of child health cards that may be relevant to the use of personal health records during adolescence;
6. Make recommendations for further developments and use of adolescent health cards/personal health records, including linkages to personal health records across the life-course.

2.2. Methods

[13] WHO (2012): WHO recommendations for routine immunization- summary tables, http://www.who.int/immunization/policy/immunization_tables/en/

[14] Lehnertz N, Broutet N, Mehl G, et al (submitted for publication): *Effective Health Interventions for Adolescents that could be Integrated with Human Papillomavirus Vaccination Programs*

The methodology included:

- A review of the available literature (articles published since 2000 from high/middle/low income countries);
- Contact with WHO Regional Advisers responsible for adolescent health and immunization/vaccines, in order to identify grey literature, programme reports and examples of personal health records for adolescents;
- Key informant contacts/interviews to obtain opinions of individuals/organizations involved with adolescent health, and examples of adolescent health cards;
- A report of the findings and recommendations for future developments.

The main impetus for the review was in the context of HPV vaccine introduction: the expansion of immunization beyond infants into older age groups, and the opportunities that this provides to link with adolescent health more generally. In exploring these synergies, it became clear that there was a need to review the use of adolescent health cards for the contribution that they might make, including recording and monitoring.

Initial contacts with experts in the field and a perusal of the literature indicated that there are a number of words in use for individual held or adolescent-accessed health-related information, including: adolescent health card, health passport, health card, health record, personal health card, patient portal, patient controlled health record and personally controlled electronic health record. This range of words was therefore incorporated into the Pub Med search that was carried out, using the following terms:

> *(("Access to Information"[Mesh] OR "Health Records, Personal"[Mesh] OR "Personal Health Record"[tiab] OR "Personal Health Records"[tiab] OR "Personal Medical Records"[tiab] OR "Personal Medical Record"[tiab] OR "Personal Electronic Health Record*"[tiab] OR "Computerized Patient Record*"[tiab] OR "health card"[tiab] OR "health cards"[tiab] OR "health passport*"[tiab])) AND (Adolescent[Mesh] OR Minors[Mesh] OR teen[all fields] OR teens[all fields] OR teenager[all fields] OR teenagers[all fields] OR teenaged[all fields] OR juvenile*[tiab] OR preteen*[tiab] OR pre-teen*[tiab] OR adolescent[text] OR youth[text] OR youths[text] OR girl*[tiab])*

In addition to the Pub Med search, contact was made with WHO Regional Advisors for Immunization, Vaccines and Biologicals (IVB) and Maternal, Newborn, Child and Adolescent Health (MCA) to solicit information about adolescent health cards. Regional Advisors responsible for adolescent health and development from some of the Regional Offices of UNICEF, UNFPA and UNESCO were also contacted.

Contact was also made with key informants in a number of International NGOs and bilateral funding agencies working in the field of adolescent health/adolescent sexual and reproductive health (ASRH), and with selected

academics and other individuals with a known interest and expertise in this field. All of the key informants who responded positively were subsequently contacted by phone to obtain additional information (see Annex 1 for the email sent to key informants and Annex 2 for the list of informants who responded).

2.3. Exclusion criteria

The primary purpose of the study was to review experiences with recording systems directed to the health of adolescents that were retained and easily accessible to adolescents (and in the case of younger adolescents their parents), and that included monitoring, treatment and care related information, with or without health messages.

There is a broad range of documents that provide and record health related information about, for and from adolescents and their families. For the purposes of the present review it was decided to exclude three groups of documents from the review (see annex 3 and 4).

First, the review would not include standardized systems that record information about adolescents' health and development, whether manual or electronic, *if the information collected is subsequently only available to service providers or retained by the health system*, including school health services. A number of such recording systems were identified through the key informants and the searches that were carried out[15] [16] [17] [18] [19] [20] [21] (Annex 4 Figures 1 and 2). Although they have been excluded from this study, knowledge about such recording systems is important because personal health records (PHRs), particularly internet-based PHRs, are often dependent on service providers having standard, systematically collected information systems and electronic medical records (EMRs).

Secondly, although one of the potential purposes of adolescent personal health cards is to provide information to adolescents and their parents, the review excluded information materials *if they were designed with the sole aim of providing adolescents with health-related information*, including the many print[22] [23] [24] and electronic materials[25] [26] [27] [28] available at national and global levels

[15] www.caah.chw.edu.au/resources/gpkit/18_Appendix_1.pdf
[16] https://www.raaps.org/
[17] Salerno, J Marshall, VD and Picken, EB: *Validity and Reliability of the Rapid Assessment for Adolescent Preventive Services Adolescent Health Risk Assessment*, Journal of Adolescent Health, 50, 595-599
[18] http://www.umsa.ch/umsa_home/umsa_presentation.htm
[19] http://new.paho.org/clap/index.php?option=com_content&task=view&id=24&Itemid=122
[20] olyaihospital.org/download4d7f.pdf?file=Guidelines1.pdf
[21] www.nrhmorissa.gov.in/pdf/School_Health_Programmes.pdf
[22] http://www.icrw.org/where-we-work/gender-equity-movement-schools-gems
[23] http://www.jhuccp.org/resource_center/media/life-choices-family-planning-campaign
[24] http://www.lunco.cfsh.info/SHIFT-pamphlets.html
[25] http://teenshealth.org/teen/

developed for this purpose (Annex 4 Figures 3 and 4). Even though such materials were not included in the review, being aware of their existence is important because it is likely that it will be more effective and feasible to provide links to such sources of information through adolescent personal health cards, rather than trying to include all the detailed information in the card itself.

The review also does not include records, whether manual or electronic, *if they were primarily developed with the intention of improving the treatment, care and transitioning of adolescents with chronic illness*. There are many of these available[29] [30] [31] [32] (Annex 4 Figures 5, 6, 7 and 8), but they are not designed for the general public of adolescents who are the focus of this present review. However there are clearly relevant lessons to be learned from such records.

Finally, the review has not included any focus on health cards that may contain some health-related information about individual adolescents but that were *designed primarily for service access and/or health insurance purposes*[33] [34] [35].

3. Results

3.1. Literature Search

From the Pub Med search 301 results were obtained (as of the most recent update of the search carried out on 05.01.13). In addition to the Pub Med search the document repositories in the WHO Offices for the South East Asia Region and the Africa Region were searched in order to identify additional grey literature and reports.

One hundred and three of these articles were selected to read the abstract based on the title of the article – if it included the word *adolescent* and/or one of the terms that had been included in the literature search as *possible descriptors of adolescent health cards*.

Eighteen full text articles were reviewed, and the references of these articles were also searched for possible additional relevant articles.

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[26] Borzekowski DLG, Fobil JN and Asante KO (2006): *Online Access by Adolescents in Accra: Ghanaian Teens' Use of the Internet for Health Information*, Developmental Psychology, **3**, 450-458
[27] http://www.nlm.nih.gov/medlineplus/teenhealth.html
[28] http://www.brook.org.uk
[29] http://www.talkback-uk.com/our-work/health-passport
[30] http://www.hdc.org.nz/about-us/disability/health-passport/download-your-health-passport
[31] http://www.healthytransitionsny.org/skills_media/tool_show/7
[32] http://www.reumanet.be/pdf/patientpassport.pdf
[33] http://www.rsby.gov.in/
[34] Sparrow, R (2008): *Targeting the poor in times of crisis: the Indonesian health card, Health Policy and Planning*, **3**, 188-192
[35] http://www.jhpiego.org/node/1236

None of the articles reviewed provided any information about hand-held adolescent personal health cards. A number provided information about the use of Personal (electronic) Health Records by/for adolescents, although none of these articles were from studies carried out in low or middle-income countries (LMICs), and in any event most of these types of records were excluded from subsequent analysis for the reason outlined above (although there is a synopsis of the findings in Annex 3).

An additional search was carried out using Google scholar, in order to identify articles and examples of both adolescent health cards and child health cards/road to health cards, the latter complementing a Pub Med search that was also carried out to identify evaluations of child health cards (see objective 5 above).

3.2. Key informant contacts

Of the 13 WHO, UNICEF, UNFPA and UNESCO Regional Offices that were contacted, 12 responded to the initial email, and of these 3 were able to provide some information about adolescent health cards (see Annex 2, Table 1).

Of the 12 International NGOs and bilateral funding agencies that were contacted, all responded, but only one was able to provide any information about adolescent health cards, and this information was limited to adolescent vaccination cards (see Annex 2, Table 1).

Of the 20 academics contacted, information was obtained from 16 of them, and two were able to provide information about adolescent health cards (although for the reasons discussed in 2.3 above, this information was mostly not subsequently included in the analysis).

A number of the UN, NGO and academic informants contacted other colleagues, but no additional information was forthcoming from these additional sources.

There were a number of examples of adolescent electronic health records and PHRs/PCHRs obtained from the key informant contacts (although none of these from LMICs), but for the reasons mentioned in 2.3 above these were not included in the subsequent analysis (see Annex 3 for an overview of the findings).

Despite the lack of information about adolescent health cards obtained from the key informants, there was wide interest and support for the focus of the review and significant interest in the findings. In addition, there were a number of respondents who indicated that they had discussed the implementation of adolescent health cards within their organizations in the past, but for a range of reasons the proposed activities had never been implemented.

3.3. Adolescent Health Cards

The core elements of paper-based adolescent health cards include personal information (e.g. name, age, sex, address); information about the adolescent's health (e.g. blood pressure, anaemia, medical problems); information about vaccines that need to be provided during this period of the life course; monitoring of weight and height (with appropriate centile charts); and some simple health-related messages (e.g. diet and physical activity) (Annex 5: Figure 9).

Any or all of these core components may be expanded, for example the details of the adolescent's vaccination status (Annex 5: Figure10); the details about the adolescent's health (Annex 5: Figure11), although such information is generally limited given the space available on the card; and health information for the adolescent and details about the adolescent's clinical records (Annex 5: Figure12a), which has the potential to be linked to a clinic-based record (Figure 12b).

In addition to such general adolescent health cards there are cards in use that deal with specific interventions, for example HPV vaccination cards for girls[36] (Annex 5: Figure 13); specific functions within the health system, such as referral[37] (Annex 5: Figure 14); and that have been designed to track inputs and outcomes related to specific projects/programmes (Annex 5: Figure 15).

Finally, in a number of countries, among them Uruguay[38] (Annex 5: Figure 16), Brazil[39] (Annex 5: Figure17) and France[40] (Annex 5: Figure 18), paper based records have been developed that not only include more information *about* the adolescent but also include much more information *for* the adolescent. These documents are generally called *health passports,* and the example from Brazil runs to 50 pages, with different versions for adolescent boys and adolescent girls.

All of the examples of adolescent health records and adolescent health passports were identified through the feedback from key informants. However, from follow-up discussions it does not appear that there have been any evaluations of the adolescent health cards identified in terms of their use and usefulness for the functions that the cards were designed to fulfil. In terms of objectives 2 and 4 of the study, for the most part it was therefore difficult to identify "best practices" from the information obtained, either from the literature search or from the key informants, or to identify specific issues that need to be taken into consideration in relation to adolescent personal health cards. The one issue that was raised by several respondents was the need for special attention to be paid to ensuring the confidentiality of the information contained in the cards.

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[36] http://www.rho.org/HPV-vaccine-implementation.htm
[37] www.who.int/entity/...delivery/.../SriLanka-school-immunization.pdf
[38] http://www.msp.gub.uy/categoria_52_1_1.html
[39] http://www.saude.ba.gov.br/index.php?option=com_content&view=article&id=142&catid=2&Itemid=17
[40] www.sante.gouv.fr/IMG/pdf/carnet_de_sante.pdf

Evaluations *are* available for some of the special-focus cards. For example vaccination cards have been shown to improve the accuracy of parent reporting for monitoring of vaccination status[41], although the there may be challenges of ensuring that the cards are actually used by parents.

3.4. Lessons learned from Child Health Cards

Child health cards have been used extensively in all regions since the development and promotion of the growth monitoring charts retained by mothers and pioneered by David Morley in Nigeria in the 1960's. This subsequently become one of the core elements of the *child survival revolution* in the early 80's, the "G" of GOBI (growth monitoring, oral rehydration therapy, breast feeding and immunization). Vaccination cards have similarly been widely used, either alone or in combination with growth monitoring charts, records of contacts with health workers and information for parents on a range of issues, including infant feeding[42]. In addition to informing and reminding parents about follow-up visits and immunization schedules, child health cards provide a record of health problems and interventions that have taken place, which is useful for both the parents and also for a range of service providers[43] (Annex 6 Figure 19).

Not only is the information about growth monitoring and immunization important at an individual level but it can also contribute to monitoring at a programmatic level, for example in assessing coverage, and such cards have been used as a source of information for both DHS and MICS surveys[44] [45].

A number of lessons have been learned over the years[46] [47] [48] including the importance of involving parents in their design[49]; that in terms of their use and usefulness there are trade-offs between the amount of information included and simplicity[50]; and the importance of being clear about the objectives of the card,

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[41] Lu PJ, Dorell C, Yankey D, Santibanez TA and Singleton JA (2012): *A comparison of parent and provider reported influenza vaccination status of adolescents*, Vaccine, 9; 30 (22): 3278-85. Epub 2012 Mar 20

[42] http://sites.google.com/site/immunizationcardrepository/

[43] http://www.aidstar-one.com/zimbabwe_child_health_card

[44] Cage, AJ, Ali D and Suzuki C (2005): *A Guide for Measuring and evaluating Child Health Programs*. MEASURE Evaluation. Carolina Population Centre, University of North Carolina at Chapel Hill

[45] Brown, J, Monasch R, Bicego G, Burton A and Boerma T (2002): *An assessment of the Quality of National Child Immunization Coverage Estimates in Population-based Surveys*. MEASURE Evaluation, Carolina Population Centre, University of North Carolina at Chapel Hill

[46] Crips NG and Donald PR (1987): *The "Road to Health" card and immunization records,* SAMJ, 72, 331-333

[47] Lancet editorial (1985) 1337-8

[48] Turner KE and Fuller S (2011): Patient-Held maternal and/or Child Health Records: Meeting the Information Needs of Patients and Healthcare Providers in Developing Countries, Online Journal of Public Health Informatics * ISSN 1947-2579 * http://ojphi.org 3, 1-48

[49] Sachs M, Sharp L, Bedford H, Wright CM (2011): *'Now I understand': consulting parents on chart design and parental information for the UK-WHO child growth charts*, Child Care Health Dev. 38(3):435-40. doi: 10.1111/j.1365-2214.2011.01256.x. Epub 2011 Jun 13

[50] Musarandega, R et al (2012): *Making patient-held cards work: Lessons from the Child Health Card Evaluation in Zimbabwe*

since child health cards may fulfil many different functions[51] [52], including: providing a record of the medical and social history of the child, details about the child's birth, recording and promoting immunization and other interventions, for example Vitamin A and de-worming, improving the parent/guardian's understanding of factors such as nutrition that affect the child's health and development, providing health education messages for parents/guardians and improving their understanding about child growth, enabling health workers to assess the child's growth and interpret this in terms of health status, monitoring the child's growth, helping the health worker identify HIV-exposed children and improving communication between parents and health workers[53].

Other lessons learned include the need to monitor the understanding of the cards by both parents and health workers, which is often suboptimal,[54] [55] [56] [57] and to assess the quality of the information that is collected[58]. Through monitoring and evaluation of the cards improvements can be made[59] [60] [61] and with adequate training, for both parents and health workers, improvements can be made in the use and usefulness of the cards, and they can be used in a range of settings[62] [63].

Similar lessons have been learned from home-based cards used by pregnant women[64] [65]. Despite the potential benefits, for example enhancing antenatal

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[51] Mahomva A, Madzima R and Miller A (2009): *Improving Identification and Follow-Up of HIV-Exposed Children in Zimbabwe* In: Marlink RG, Teitelman ST, eds. *From the Ground Up: Building Comprehensive HIV/AIDS Care Programs in Resource-Limited Settings*. Washington, DC: Elizabeth Glaser Pediatric AIDS Foundation; 2009. http://ftguonline.org.

[52] www.health.go.ug/nutrition/docs/.../Child_Health_Card_Colour.pdf

[53] Lakhani AD, Avery A, Gordon A and Tait N (1984): *Evaluation of a home based health record booklet, Archives of Disease in Childhood*, 59, 1076-1081

[54] Schoeman SE, Hendricks MK, Hattingh SP et al (2006): *The targeting of nutritionally at-risk children attending a primary health care facility in the Western Cape Province of South Africa*, Public Health Nutr. 9(8), 1007-12

[55] Harrison D, Heese HD, Harker H, Mann MD (1998): *An assessment of the 'road-to-health' card based on perceptions of clinic staff and mothers*, S Afr Med J. 88(11):1424-8

[56] Kumar R (1993): *Streamlined records benefit maternal and child health care*, World Health Forum, 14, 305-307

[57] Ruel MT, Pelletier DL, Habicht J-P et al (1991): *Comparison of Two Growth charts in Lesotho: Health Workers' ability to Understand and Use them for Action*, Am J Public Health, 81, 610-616

[58] Babu, GR et al (2011): *Evaluation Of Immunization Cards And Parental Recall Against Gold Standard For Evaluating Immunization Coverage*

[59] Harrison D, Harker H, Heese H, Mann MD (2005): An assessment by nurses and mothers of a 'Road-to-Health' Book in the Western Cape, Curationis. 28(4), 57-64

[60] Usman HR, Rahbar MH, Kristensen S et al (2011): Randomized controlled trial to improve childhood immunization adherence in rural Pakistan – redesigned immunization card and maternal education. Tropical Medicine and International Health, 16, 334-342

[61] Kumar R (1993): *Streamlined records benefit maternal and child health care*, World Health Forum, 14, 305-307

[62] Aden AS, Brännström I, Mohamud KA, Persson LA, Wall S (1990): *The growth chart--a road to health chart? Maternal comprehension of the growth chart in two Somali villages*, Paediatr Perinat Epidemiol. 4(3), 340-50

[63] McMaster P, McMaster HJ and Southall DP (1996): *Personal Child Health Record and Advice Booklet programme in Tuzla, Bosnia Herzegovina*, Journal of the Royal Society of Medicine, 89, 202-204

[64] Ghosh, S (1985): *Evaluation of a home based antenatal card*. J Trop Pediatr, 31, 39-42

attendance and contributing to the detection of high-risk pregnancies, if the cards are to be used there is a need to ensure adequate education and training of women and health workers, and adequate supervision and monitoring of the reliability of the data recorded on the cards.

3.5. The use of mobile phones and internet

The initial motivation for this review was the need to synthesize lessons learned from paper-based health records for adolescents that might contribute to strengthening and linking programmes for adolescent health, including the roll out of new vaccines for this target population. However, it became clear from both the literature review and the key informant interviews that it would also be important to review the use of m-technologies.

With the growing penetration of mobile phones and the rapid development of mobile phone technologies, there has been increasing attention paid to the use of mobile phones for health (mHealth), including for a number of the functions that adolescent health cards have been designed to fulfil, such as reminding[66] [67] [68] (e.g. about vaccination schedules), informing[69], providing health messages[70] [71], contributing to behaviour change[72] and improving patient care[73] [74] [75].

Mobile phones have a number of potential advantages over paper health cards, for example they can be personalized and interactive, they are convenient and they blend with the lifestyles of many adolescents, even in LMICs, and reminders (for appointments, vaccines, follow up) can be sent in real time as needed, not recorded possibly months or weeks in advance with the hope that adolescents will actually look at their card at the right time. However, there appear to be few

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[65] Laurell L, Essen B, Pena R, Ostergren PO and Liljestrand J (1994): *A study of the use of the Nicaraguan antenatal card*, Journal of Tropical Pediatrics, 40, 133-6.

[66] http://www.columbia.edu/cu/text4health/

[67] http://bedsider.org/reminders

[68] Kharbanda EO, Stockwell MS, Fox HW and Rickert VI (2009): *Text4Health: a qualitative evaluation of parental readiness for text message immunization reminders*, Am J Public Health, 99, 2176-2178

[69] http://quintepediatrics.com/patients/apps-we-love/

[70] http://www.actforyouth.net/resources/pm/pm_media_1009.pdf

[71] htttp://www.fhi360.org/m4rh

[72] Gurman TA, Rubin SE and Roess AA (2012): *Effectiveness of mHealth Behaviour Change Communication Interventions in Developing Countries: a Systematic Review of the Literature*, Journal of Health Communication: International Perspectives, 17: sup1, 82-104

[73] Dowshen N, Kuhns LM, Johnson A et al (2012): *Improving Adherence to Antiretroviral Therapy for Youth Living with HIV/AIDS: A Pilot Study Using Personalized, Interactive, Daily Text Message Reminders*, *J Med Internet Res; 14(2):e51* doi:10.2196/jmir.2015

[74] Frøisland DH, Arsand E and Skårderud F (2012): *Improving diabetes care for young people with type 1 diabetes through visual learning on mobile phones: mixed-methods study*. J Med Internet Res. 2012 Aug 6;14(4):e111. doi: 10.2196/jmir.2155.

[75] L'Engle K and Vadhat H (2009): *Mobile Phone Interventions for Reproductive Health (M4RH): Testing the Feasibility of Text Messaging to Improve Family Planning*, Progress in Family Planning, FHI

examples of evaluations that have been carried out to assess the use and usefulness of mobile phones for adolescent health, and their role is likely to be limited for some of the functions that adolescent health cards aim to achieve, in particular information for service providers (e.g. programme monitoring).

None the less, a number of key informants stressed the importance of the mobile technologies currently available and that smart phones in particular should be the focus of future investments: "their abilities to link adolescents, providers, parents, educators, in fact all the players in adolescent health, are unsurpassed and only getting better". Smart phones can also provide a platform that evolves throughout the life span, thus avoiding lapses in contact and care.

In terms of concerns about confidentiality, walls can be built around data/information that should not be shared. The adolescent can have control over the content (both what they input and what they accept from providers) and different users can have different levels of access, virtually eliminating any confidentiality issues around the quantity of information that can be shared or sent.

However, there are a number of challenges that will need to be overcome with m-technologies. For example, in the MyHealth Passport project at the Sick Children's hospital in Toronto[76], young people are encouraged to password protect their phone, so in an emergency it may difficult to access the stored information; furthermore, while many adolescents have mobile phones, in many places they only have voice and text messaging, so there is a need for the development of text message-based apps. While m-technologies provide new opportunities, the evaluation of the MyHealth Passport[77] indicated that the young people wanted something in print that they could carry, which came as a surprise to the programme staff, who had assumed that adolescents would prefer an electronic format. In general, while promising, the use of m-technologies requires further evaluation[78].

The Ottawa Hospital Research Institute (OHRI) has recently released a mobile app[79] that greatly increases adolescents' and parents' access to vaccination information, keeping immunization records updated, sending a backup copy via email, providing vaccination reminders and issuing alerts about outbreaks of preventable diseases in the community. The app also provides quick links to information on vaccines and how to deal with adverse reactions.

In addition to mobile phone-based technologies, the Internet has also been used to fulfill some of the functions of adolescent personal health cards, recording and

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[76] http://www.sickkids.ca/Good2Go/Transition-Interventions-Tools/MyHealth-Passport/index.html

[77] Wolfstadt J, Kaufman A, Levitin J and Kaufman M (): *The Use and Usefulness of MyHealth Passport: an Online Tool for the Creation of a Portable Health Summary*, International Journal of Child and Adolescent Health, Special Issue on "Youth Health Care Transition", 3, 499-506

[78] de Jongh T, Gurol-Urganci I, Vodopivec-Jamsek V, et al (2012): *Mobile phone messaging for facilitating self-management of long-term illnesses*, Cochrane Database Syst Rev. 2012 Dec 12;12:CD007459. doi: 10.1002/14651858.CD007459.pub2.

[79] http://www.ohri.ca/newsroom/newsstory.asp?ID=327

reminding about vaccinations, for example[80] [81]. A large number of other examples of electronic health records were also identified in the literature search and from key informants, but these were mostly excluded from subsequent analysis because they were either primarily service-provider-based or they were designed to improve the treatment, care and transitioning for a specific chronic disease (see Annex 3 for a synthesis of the lessons learned from electronic records). There are also examples of projects that have combined paper, mobile phones and the Internet, such as the MyHealth Passport, that link different recording systems and different templates.[82]

4. Discussion

It has clearly not been possible to identify all publications and reports, or all examples of adolescent health cards through this exploratory review. Despite the positive response from UN Regional Offices, International NGOs and other selected key informants it is most unlikely that they would be aware of all activities in countries related to adolescent health cards[83].

The general lack of use of adolescent health cards, despite the widespread use of child health cards and the obvious interest from a number of key informants, is perhaps surprising. It may be reflective of a number of factors, including the relative lack of attention that has been paid either to the provision of health services for adolescents or to the monitoring of milestones that have important implications for adolescent health[84] and development, and transitions to adulthood; or to the lack of vaccination programmes for this age group. However, several of these factors are changing, and this review has raised a number of issues that could both influence the use of adolescent personal health cards in school age and adolescent vaccination programmes and also in the provision of health services for adolescents more generally.

The first challenge is one of nomenclature: there are currently a number of different words in use that are not used consistently and that are used in an overlapping way to describe a range of functions through a range of media (paper, mobile phones and the internet). It is therefore important first to be clear about the main functions for which adolescent personal health cards are, or might be used in terms of health promotion, clinical care, monitoring and

[80] https://www.mesvaccins.ch/login.html;jsessionid=D6000B69B7FD277DED46D43F21A6BBC4
[81] http://streaming.cdc.gov/vod.php?id=b65b41271643b6aeb6743a36b7ac4f7820110518145116152
[82] Http//www.sickkids.ca/myedupassport
[83] By way of example, the author came across an example of an Adolescent Health Passport in Ghana that was not available on the internet and not known about by any of key informant interviews; similarly the use of child/adolescent cards in Bhutan and Lesotho is referenced by key informants, but no hard or soft copies were obtained; in addition, it was not possible to obtain any response from WHO EMRO (although an academic institution in the region responded), a region where significant developments in school health have taken place, including school-based recording.
[84] See for example Judith Bruce's proposed 12 year old check-in

improving communication between the home/family and the health system. These include:

- Reminding people (e.g. immunization, medical appointments)
- Monitoring health and disease, both at individual and population levels (e.g. for programme performance assessment)
- Providing information to adolescents, parents and service providers (health literacy and education)
- Improving care (e.g. adherence to medication)
- Facilitating referral
- Supporting transitioning: child to adolescent and adolescent to adult
- Empowering adolescents, by helping them take more control over decisions about their health, in the light of their evolving capacities.

Although a small number of paper-based adolescent health cards were identified through the key informant contacts, none of these had been evaluated in terms of their benefits to the adolescent, their parents, health providers or the health system. A number of evaluations of child heath cards were identified, and it is likely that many of the lessons learned will also apply to adolescent health cards, with the proviso that while child health cards are primarily designed for parents, adolescent health cards would need to take into consideration the growing autonomy of the adolescents during this period of rapid development and growing independence.

There are clearly important opportunities for using mobile phone and internet based-technologies, and although the current focus and practice builds on paper/card, the future potential is likely to be something mobile, digital and alive, that can seamlessly connect adolescents with various providers, whether school- or health system-based.

The review identified a number of recording systems for adolescent health over and above the paper-based adolescent health cards. These have mostly been excluded from the review because in general they were primarily designed to improve the management of illness in adolescents. However, the key lessons learned from PHRs and PCHRs (summarized in Annex 3) raise a number of relevant issues that need to be taken into consideration when developing adolescent health cards, particularly if it is envisaged that mobile phones or internet based technologies might be used in addition to paper-based records:

- **Who is the target group:** all adolescents, adolescents with (often specific) chronic illness, at-risk adolescents (e.g. homeless adolescents)? In general, adolescent health cards have been designed to be used by the general population of adolescents, while PHRs and PCHRs are more often designed for adolescents with specific health problems.

- **Who controls the card**: who determines the content and fills in the information: the adolescent, the adolescent and his/her parents or the service provider? For the most part these recording systems are predominantly provider controlled, although there is some evidence that

placing more control in the hands of the adolescents may encourage them to engage more.

- **Who is/are the primary end-user/s**: the adolescent, the adolescent and his/her parents, the health workers and/or other service providers, or other organizations, for example health insurance agencies? The answer to this question has a number of implications, and may be particularly important for vaccination programmes that target younger adolescents, since much of the information that might be included is more likely to be directed to parents and health workers than the adolescents themselves. If the cards were to be designed with an older group of adolescents in mind, they could be designed to be under the control of the adolescent, rather than his/her parents.

- **What is the entry point/rationale/primary purpose**: for example is the card a component of adolescent-friendly health services, or designed primarily to improve the treatment of chronic conditions or to increase uptake of vaccination programmes and other services? Linked to this is the need for clarity about the primary purpose of the personal health record, particularly in relation to the selection of indicators to be monitored in terms of health status or interventions.

In addition to these specific questions, there are more general issues that need to be taken into consideration. First, most of the examples of adolescent health cards, mHealth approaches and adolescent PHRs/PCHRs are from small-scale projects. If adolescent health cards are to be used in a sustainable way to any significant scale, it is important to be clear about the opportunities and limitations of the existing health system and organization of services, particularly as this relates to the provision of services for adolescents.

Linked to this is the need to be aware of and take into consideration the existing vision in the country about health cards more generally: should adolescent health cards be stand alone cards; how would they be managed across the life-course of the adolescent, and how might they be integrated with family health cards or cards that are gradually added to over the life course of the individual (childhood, adolescence, adulthood and old age)?

Adolescent personal health cards also need to be seen within the overall context of how information is collected about adolescents' health and their interaction with the health system, for example improving the capacity of the health system to record clinic attendances of adolescent clients, through computerized databases, in those situations where sufficient resources are available and in places, urban areas in particular, where adolescents are likely to attend a range of facilities in sufficient numbers[85].

It is important to bear in mind the developing capacity of adolescents during this period of development and transition. Significantly, in this regard, a number of

[85] Save the Children Fund, Metro Manila, Philippines

key informants raised the issue of confidentiality in their responses. For electronic systems there has been extensive work carried out to ensure confidentiality of the data included in PHRs and PCHRs. However, this is also an issue for paper cards and for the use of mobile technologies: what information to include and how to ensure that only the adolescent, and those that the adolescent designates, have access to this information. Clearly this is of greater concern for older adolescents in relation to problems and interventions related to sexual and reproductive health, substance use and mental health.

5. Recommendations and Next Steps

5.1. General

There are a number of general questions that need to be answered before developing adolescent health cards:

- What function is the card meant to fulfil?
- Who is the card primarily for (adolescent, parents, health workers), who will control the input and access, and in terms of adolescents, for which age group is the card designed?
- What information needs to be included and in how much detail?
- What is realistic/feasible/relevant (in terms of the health system, available resources, and any existing personally held health cards for other age groups)?
- What is possible in terms of family/culture (for example, how "confidential" would an adolescent be able to keep such a card)?

In the development of adolescent health cards at country level it would be important to:

- Obtain information from adolescents about: what they would like health workers to know about them; what they would like to record that would be helpful to them (and how would they like it recorded: paper, phone, etc.); and what they do *not* want recorded on the card?
- Obtain information from service providers and others: what would health workers like adolescents to know about their health and disease that could support health promotion and treatment/care; what general information do they think would be useful for adolescents to have (actual information or linkages to where they can get information); what information would it be useful for health workers to have recorded on an adolescent health card that would assist with interventions, monitoring and referral?
- Build on what exists (e.g. vaccination cards as an entry point)
- Identify opportunities to link m-technologies and internet-based information sources with the adolescent health card, taking into consideration their various advantages and disadvantages

- Ensure a system for monitoring the cards use and usefulness to both the individuals and to health workers and programme managers (e.g. their use in monitoring)
- Start with simple non-sensitive information: personal information (date of birth, sex, etc.); height and weight; vaccination status; health problems (that the adolescent would like to share).
- Explore the potential to use the card for demand creation (e.g. to inform parents and adolescents of the benefits of selected interventions)
- Explore the potential to use the card for obtaining consent (e.g. in relation to vaccination and de-worming programmes)
- Explore the possibilities for extending child immunization cards or child health cards to include older children and adolescents, with a view to developing a life-course card.
- Explore the possibility of developing (a) a card that would focus on vaccination and other specific interventions such as de-worming for older children and younger adolescents (e.g. 6-14 year olds), based on school health services; and (b) a more personal passport for older adolescents (15-19 years) that would be more under their control and could include relevant topics such as ASRH (and if mHealth technologies were to be used there could be different access setting for different chapters of the same "card").

5.2. Vaccination programmes

Vaccination cards may provide a useful entry point for the development of adolescent health cards, building on current experiences with both child and adolescent vaccination cards. To this end, WHO could consider developing a template for a basic card that could be adapted by countries, to include the following data/information:

- **Basic personal information**: name, sex, date of birth, and school class (for school-based vaccine strategies)
- **Vaccines provided during adolescence**: dates when vaccinated, dates for next dose (for health facility or community-based strategies this could be linked to a m-reminders)
- **Adverse events**: a space for the vaccination team or local health workers to note any adverse events
- **Additional interventions**: a space to record additional interventions that might be integrated with vaccine delivery (e.g. visual screening, antihelminthics)
- **Referral**: a space for referral to health facilities (e.g. for iron folate, HIV testing and ASRH services)
- **Sexual and reproductive health information**: some basic SRH information for the adolescent (including making the links to any ASRH education being implemented in the school)
- **Links**: address, phone, internet links to relevant information sources on vaccines for the adolescent age group, and organizations working on ASRH/adolescent health, including local "adolescent-friendly" health facilities

In order to support the development and use of vaccination cards for adolescents that take a broader approach, WHO could start by linking vaccination cards to any additional interventions that might be considered for integration with adolescent vaccines. This could include using the cards to strengthen the linkages between schools and health facilities. To stimulate such developments it would be important to:

- Identify Ministries of Health, UN, NGO and other partners that might be interested to support the development and implementation of such cards (including as an entry point for adolescent health cards more generally)
- Develop an information brief explaining to countries the potential benefits of using a card to support the vaccination programmes; the potential for the card to inform/record/remind/obtain consent for vaccination and other health interventions; and what needs to be done if the card is to be used effectively (e.g. information for adolescents and parents, training for vaccination teams, teachers and health facility staff)

5.3. Adolescent health service delivery

In order to support the development of adolescent health cards more generally, WHO could consider the following next steps:

- Agree on language to describe the cards in such a way that allows for potential linkages with or use in m-technologies and internet-based strategies (e.g. Adolescent Personal Health Cards)
- Support the evaluation of adolescent health cards (SEARO) and adolescent passports (PAHO) that are currently being used in health service delivery programmes for adolescents: what is useful and used, and by whom (e.g. growth monitoring, Tanner staging) - it will be important to gather more evidence on the effectiveness of adolescent personal health cards currently in use before investing in further developments.
- Based on the outcome of these evaluations, develop a prototype card that - in addition to the relevant elements of the template presented above in 5.2 - also takes into consideration: the changing role of parents and the growing autonomy of adolescents during this phase of development; a range of epidemiological scenarios, in terms of priority diseases; and the potential for linking health facilities and school health services.
- Develop a range of strategies depending on what is feasible: decide on what is the most appropriate/do-able mix of media for achieving the overall aims of the adolescent personal health record (i.e. regular post, email or mobile phone alerts, internet-based electronic files)
- Identify UN and NGO partners to support the adaptation and piloting of the card in selected countries, which might have particular relevance in relation to programmes directed to adolescents living with HIV and other chronic illnesses, including non-communicable diseases and disabilities
- Support and evaluate the use of mobile phones in connection with the development of adolescent personal health cards, including the development of specific apps, and ensure that evaluation studies are carried out to assess their use and impact

- Given the widespread use of provider controlled electronic health records (EHRs) in the Americas region, explore with PAHO the possibility to evaluate the use of these EHR and to explore the potential to develop linkages to personally controlled health records for adolescents in selected countries.

6. Conclusions

Personally retained health cards have contributed to child health and maternal health services, both at individual and also at programmatic levels, provided that the objectives are clear and there is sufficient education, training, supervision and monitoring of both clients and service providers.

From the present review of adolescent personal health cards it is not possible to draw any strong conclusions about the use of such cards in the context of service delivery for adolescents. Although some examples of different types of adolescent personal health cards were identified, none of them had been evaluated. A recommendation from the review is therefore to support evaluations of the adolescent personal health cards currently in use in order to identify lessons learned.

It is likely that vaccination cards will be developed and used for adolescents as the number of vaccines available for this age group increase. In view of the fact that there is potential to integrate other health interventions into vaccination programmes that target adolescents (one of the pre-requisites for GAVI HPV vaccination demonstration projects is to assess the feasibility of such integration), vaccination programmes may prove a useful entry point for exploring the use of adolescent personal health cards more widely.

Concerning the use of adolescent personal health cards in routine health services for adolescents, these may prove to be useful during early adolescence, where the cards are likely to be directed to both the adolescents and their parents, and in later adolescence, when they could be more directed to adolescents themselves, in view of their evolving capacities and growing independence. Personal records in this age group are likely to touch on sensitive issues, relating to sexual and reproductive health for example, so it will be important to give adequate attention to issues of confidentiality.

Adolescent personal health cards could fulfil a range of functions, including: reminding people about appointments; monitoring health, at individual and population levels; providing information to adolescents, parents and service providers; improving treatment and care, facilitating referral and supporting transitioning; and even empowering adolescents by giving them a tool to help them take responsibility for their own health and their contacts with health services. They may also have the potential to strengthen linkages and collaboration between different service providers and different sectors (e.g.

health and education around school health services) and contribute to programme management, including monitoring.

While this review focused predominantly on paper-based cards for recording, the literature search and key informants interviews identified a number of examples of the use of mobile phones, computers and the internet for some of the potential functions adolescent personal health cards fulfil. For the most part these were either retained by the health system or had been designed for use in a clinical context, for example to improve the treatment and care of chronic illness in adolescents. While these examples were therefore subsequently not included in the review, the use of such technologies does warrant further exploration and development.

A number of next steps have been outlined for the use of adolescent personal health cards in adolescent-targeted vaccination programmes and in the overall provision of health services to adolescents, including the need to evaluate the current use of such cards in these different settings. Such developments will need to build on the use of health cards in other age groups, for example the road-to-health cards used for children under five, and will need to take into consideration national plans for the use of health cards across the life course. This in turn requires clarity about what is useful, for individuals and service providers, to be noted and tracked by an individual about their health over the life-course.

Annex 1: Contact email sent to key informants.

Dear ….

I am working with colleagues in the Department of Immunization, Vaccines and Biologicals, WHO Geneva, to review experiences of using personal health records for adolescents (adolescent health cards).

Child health personal records (child health cards) have proved to be a simple, cheap, practical and effective means of promoting and monitoring children's health, contributing to the early detection and prevention of childhood illness, and supporting national systems for surveillance and programme monitoring. They can provide important information for parents and health workers on a range of issues including birth data, growth, immunization, neurological development and episodes of illness.

There is growing attention being paid to adolescent health, both in general and also in relation to specific interventions such as HPV vaccination (the main stimulus for this particular piece of work), male circumcision for HIV prevention, HIV counseling and testing (HCT), and screening in school health settings. Personal health records for adolescents have the potential to contribute to such programmes by providing important details about adolescents' health and development, for their parents, for health workers and programme planners, and of course for adolescents themselves; they can potentially help with health care transitions/referral and may also be useful for communicating to adolescents about their own health.

We will be carrying out a review of the literature and plan to interview a number of key informants. The review will take place over the next two months and we would welcome your thoughts/inputs at this stage of the project's development, and down the road your involvement with reviewing the draft report.
To this end, I would be very grateful to receive:

- Any copies/links to reports, evaluations, case studies or other grey literature that you are aware of that focuses on adolescent personal health records/cards;
- The names and contacts (organization, position, email and phone if possible) of any key informants that you think that we should talk to for information/experiences about adolescent personal health records;
- Examples of adolescent personal health records that you know of (and places where we could access them, such as websites), and country programmes that we could learn from;
- Thoughts or reflections that you may have about adolescent personal health records: opportunities and challenges, and issues that you think we should explore in the project.

If you would like any additional information please do not hesitate to contact me, and *I would be very grateful if you would forward this email to other colleagues in … that you think might be in a position to provide any of the information being requested*.

We look forward to hearing from you and to having you engaged with this work.
We would of course be happy to send you a copy of the final report when it is completed.

Many thanks and warm regards,

Annex 2: Results from Key Informant Contacts

Table 1: Key Informant requests for examples and experiences of adolescent health cards

UN	Reply	Result	Bilaterals/ NGOs	Reply	Result	Academic	Reply	Result
WHO HQ	✔	✔	CRS	✔	✗	Australia	✓✓✓	✗✗✗
UNICEF HQ	✔	✗	DFID	✔	✗	Armenia	✓	✗
UNFPA HQ	✔	✗	FHI	✔	✗	Canada	✓	✗
UNESCO HQ	✔	✗	IPPF	✔	✗	India	✓	✗
AFRO	✔	✗	MAMTA	✔	✗	Lebanon	✓	✗
UNFPA SA	✔	✗	OXFAM	✔	✗	Nigeria	✓	✗
SEARO	✔	✔	PATH	✔	✔	Switzerland	✓✓	✗✗
WPRO	✔	✗	Pathfinder	✔	✗	UK	✓✓	✗✗
UNFPA BKK	✔	✗	Pop Council	✔	✗		✗✗✗	
UNESCO BKK	✔	✗	SCF	✔	✗	USA	✓✓✓	✗✗✗
PAHO	✔	✔	Swiss FOPH	✔	✗		✓✗	✗
EURO	✔	✗	USAID	✔	✗			
EMRO	✗	✗						

Academic Key Informants:

Australia
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Doug Kirby
ETR Associates
John Santelli
Mailman School of Public Health, Columbia University, New York

Annex 3: Electronic Personal Health Records

The initial terms of reference for this review included the term "personal health records", and this was therefore included as an element of the Pub Med search that was carried out. However, it became clear from an initial perusal of the literature that this term has a very specific meaning that is different in many ways from the original focus of the review.

Personal health records (PHRs) or electronic personal health records (EPHR) are *electronic applications through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure and confidential environment*[86]. PHRs are usually divided into two groups: the *tethered* PHRs, which are normally sponsored by an organization and essentially make information that exists in electronic medical records (EMRs) available to the "patient", they are available from a number of sources on the internet and generally are very clinically oriented[87] [88] [89] [90] [91]; and *untethered* PHRs that are more under the control of the "patient", and are often called personally controlled health records (PCHRs)[92] [93].

There has been growing experiences with using PHRs and PCHRs with adolescents[94] [95] [96] [97], for specific groups of adolescents, such as homeless adolescents[98] and for specific clinical functions, for example treatment and adherence[99]. The different applications that can be used in the development of

[86] http://www.markle.org/health
[87] http://www.dossia.org/
[88] http://www.nlm.nih.gov/medlineplus/personalhealthrecords.html
[89] http://www.medicare.gov/manage-your-health/personal-health-records/personal-health-records.html
[90] http://www.aetna.com/showcase/phr/
[91] www.healthvault.com/
[92] Mandl KD, Simons WW, Crawford WCR and Abbett JM (2007): *Indivo: a personally controlled health record for health information exchange and communication*, BMC Medical Informatics and Decision Making, 7, 25.
[93] Bourgeois FC, Taylor PL, Emans SJ et al (2008): *Whose Personal Control? Creating Private, Personally Controlled Health Records for Pediatric and Adolescent Patients*, Journal of the American Medical Informatics Association, 15, 737-743
[94] Pediatric Practice Action Group and Task Force on Medical Informatics (1999): *Privacy Protection of Health Information: Patients rights and Pediatrician Responsibilities*, Pediatrics, 104, 973
[95] Council on Clinical Information Technology (2009): *Using Personal Health Records to Improve the Quality o Health Care for Children*, Paediatrics, *124*, 403
[96] American Academy of Pediatrics (): *Policy Statement – Using Personal Health Records to Improve the Quality of Care for Children*
[97] Britto, MT and Wimberg J (): *Pediatric Personal Health Records: Current Trends and Key Challenges*, Pediatrics
[98] https://www.healthshack.info/
[99] http://www.projecthealthdesign.org/projects/round-1-projects/my-medi-health

PHRs allow for a range of possibilities[100] [101] and can, among other things, greatly expand the information, and the sources of data that can be included in the adolescent's record[102]. PCHRs can play an important role in supporting the transitioning of adolescents with chronic illness[103], and efforts are being made to combine different approaches to better meet the needs of service providers and the adolescents using the services[104]. However, there have been few evaluations of the use of PHRs or PCHRs by adolescents[105], and in general despite initial enthusiasm[106] they have not always lived up to their promises[107]. Issues of storage and access are likely to require on-going attention.

Table II provides an overview of the potential functions of adolescent personal health cards and compares the relative benefits of the different media (paper, phones, computers/internet) in fulfilling these functions.

In the absence of any formal evaluations, Table III makes an attempt to highlight some advantages and disadvantages of the various media that are being used to carry out the different functions that have been synthesized.

[100] Brennan, PF, Downs S and Casper G (2010): *Project HealthDesign: Rethinking the power and potential of health records*, Journal of Biomedical Informatics, 43, 53-55

[101] Chira, P et al (2010): *Living Profiles: Design of a health media platform for teens with special healthcare needs*, Journal of Biomedical Informatics, 43; 509-512

[102] Archer, N et al (2011): Personal Health Records: Scoping Review, J Am Med Inform Assoc, 18, 515-522

[103] Weitzman ER et al (2011): Helping High-Risk Youth Move through High-Risk Periods: Personally Controlled Health records for Improving Social and Health Transitions, Journal of Diabetes Science and Technology, 5

[104] http://www.sickkids.ca/Good2Go/What-we-do/MyHealth-Passport/index.html

[105] Wolfstadt J, Kaufman A, Levitin J and Kaufman M (2010): *The Use and Usefulness of MyHealth Passport: an Online Tool for the Creation of a Portable Health Summary*, International Journal of Child and Adolescent Health, Special Issue on "Youth Health Care Transition", 3, 499-506

[106] Steinbrook R (2008): *Personally Controlled Online Health Data – the Next Big Thing in Medical Care*, N Engl J Med, 358

[107] Kellermann, AL and Jones SS (2013): *What It Will Take To Achieve The As-Yet-Unfulfilled Promises Of Health Information Technology*, Health Affairs, 32, Issue 1

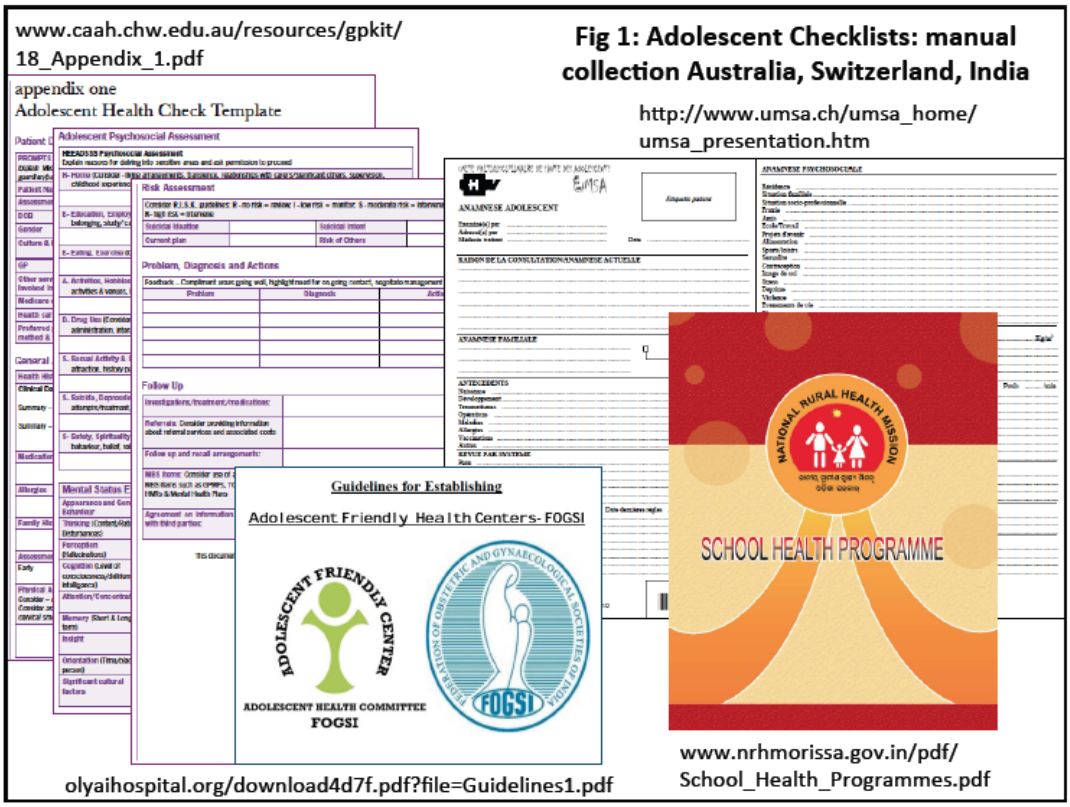
Table II: A comparison of different media for achieving the functions of adolescent health cards

MEDIUM	FUNCTION					
	Informing & Educating	Reminding & follow-up	Tracking & Referral	Improving Care	Transitioning Empowering	Programme Monitoring
Paper	++	+	++	+	+	++
Phone	++	++	+	+	+	+
Computer	++	+	++	++	++	++
Combined (all of above)	++	++	++	++	++	++

Tale III: Advantages/disadvantages of different media for achieving the functions of adolescent health cards

MEDIUM	Advantages	Disadvantages
Paper	Cheap Easy to access	Limited amount of information Not easy to update, not robust Confidentiality
Phone	Increasing access Part of adolescents lives Interaction possible	May require smartphone Confidentiality
Computer	Able to link to information sources and health records	Limited access in LMICs Requires EMRs Confidentiality
Combined	Adapt to function Adapt to available resources More than the sum of the parts	Access to the technology Confidentiality Development costs

Annex 4: Excluded Health Cards (Figures 1 – 8)



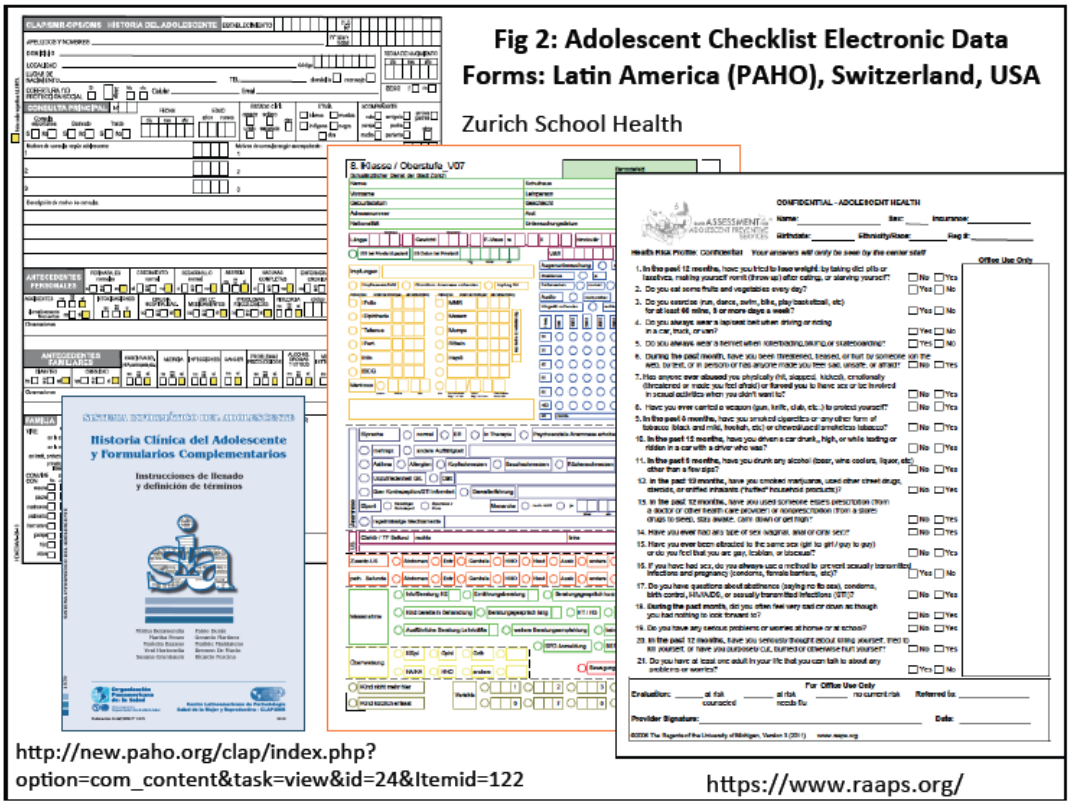
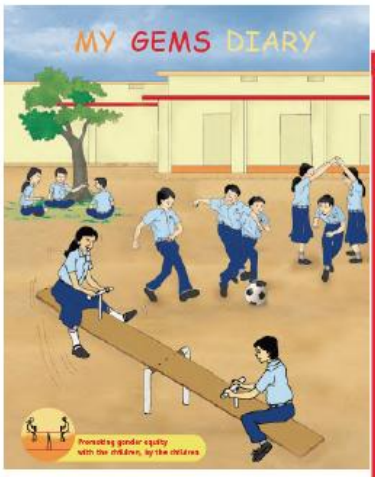
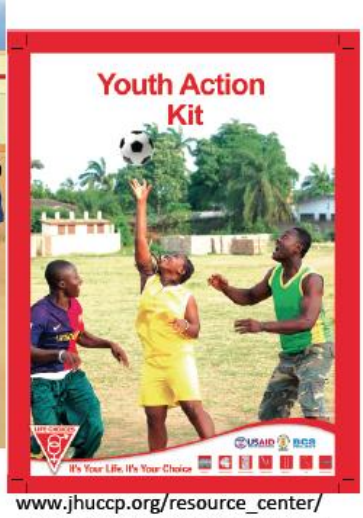


Fig 3: Printed health information materials for adolescents: India, Ghana, Canada



www.icrw.org/where-we-work/gender-equity-movement-schools-gems



www.jhuccp.org/resource_center/media/life-choices-family-planning-campaign

www.lunco.cfsh.info/SHIFT-pamphlets.html

Fig 4: electronic information for adolescents

http://teenshealth.org/teen/

http://www.brook.org.uk

http://www.nlm.nih.gov/medlineplus/teenhealth.html

Figure 5: Improving communication with service providers: a client controlled Passport for people with (learning) disabilities (UK)

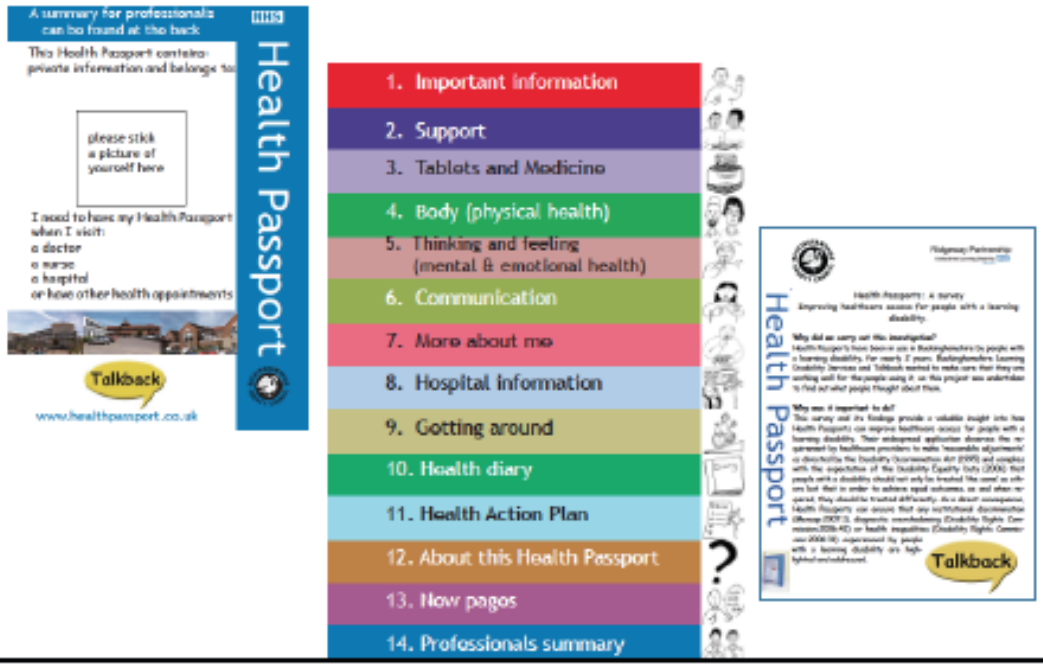


Figure 6: Health passport New Zealand (client controlled): what people living with disabilities would like health workers to know about them

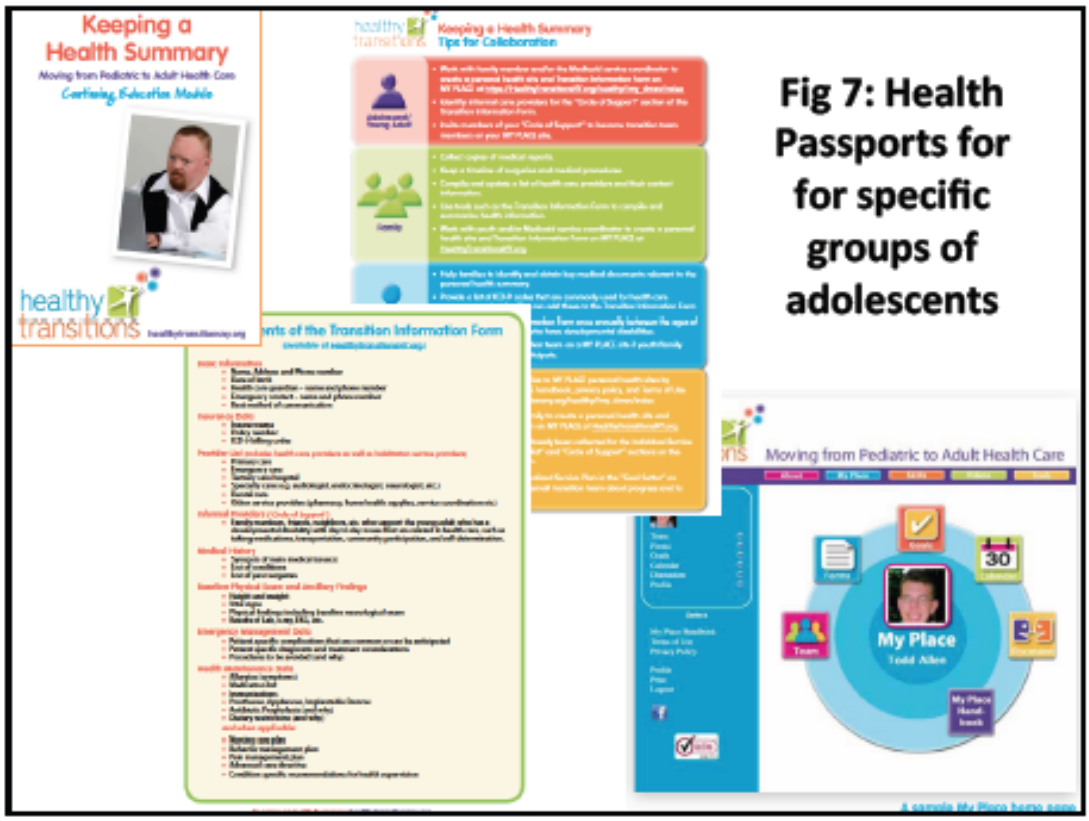


Fig 7: Health Passports for for specific groups of adolescents

Fig 8: Health Passports for adolescents with specific health problems

Annex 5: Examples of Adolescent Health Cards (Figures 9 -18)

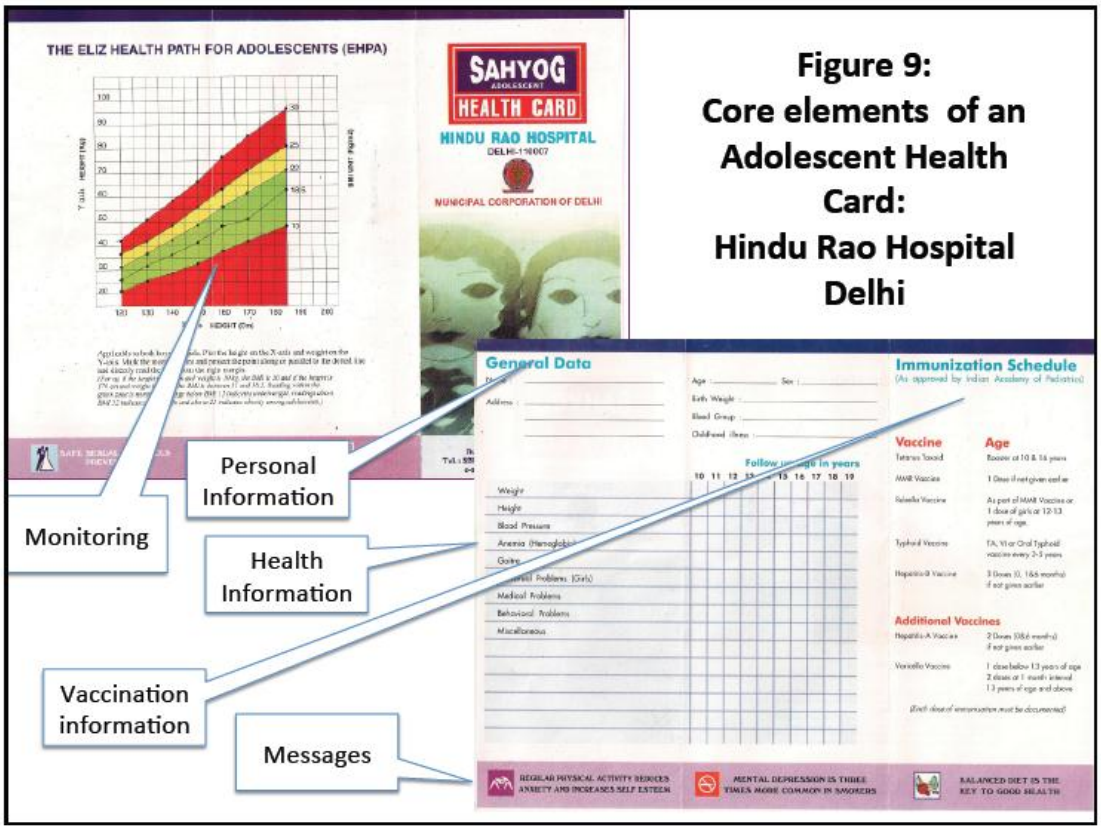


Figure 9: Core elements of an Adolescent Health Card: Hindu Rao Hospital Delhi

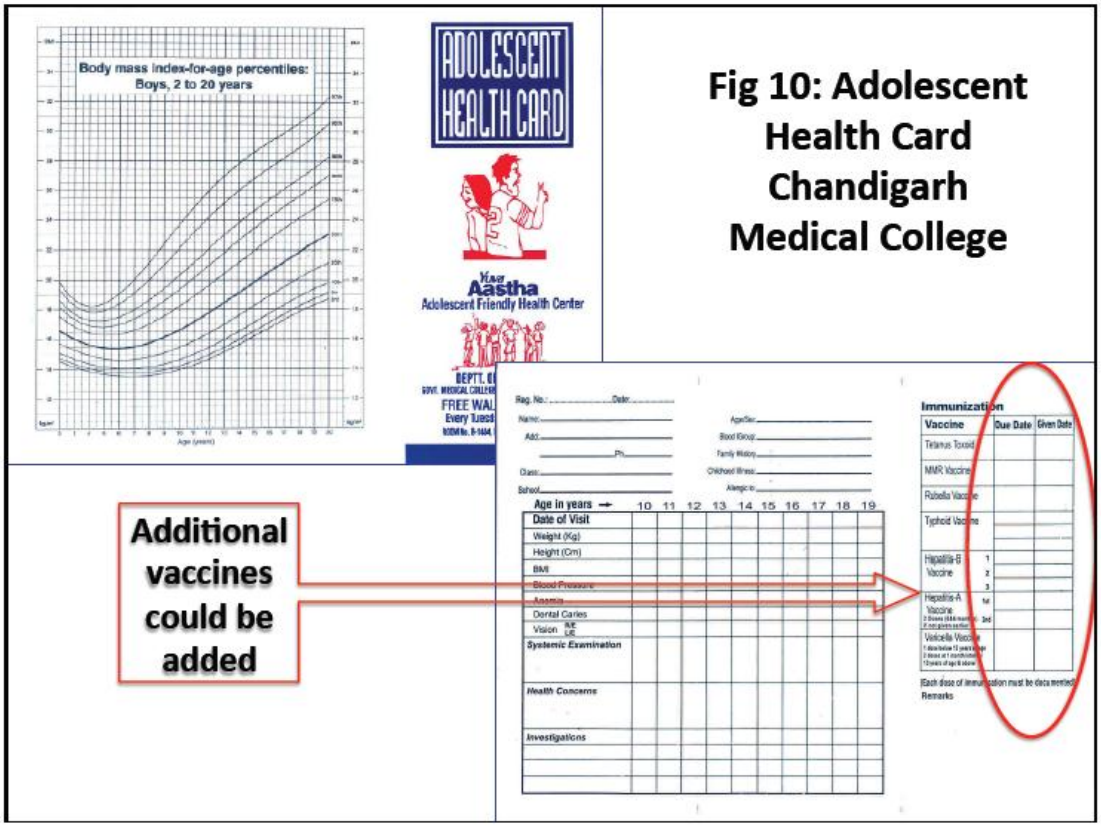


Fig 10: Adolescent Health Card Chandigarh Medical College

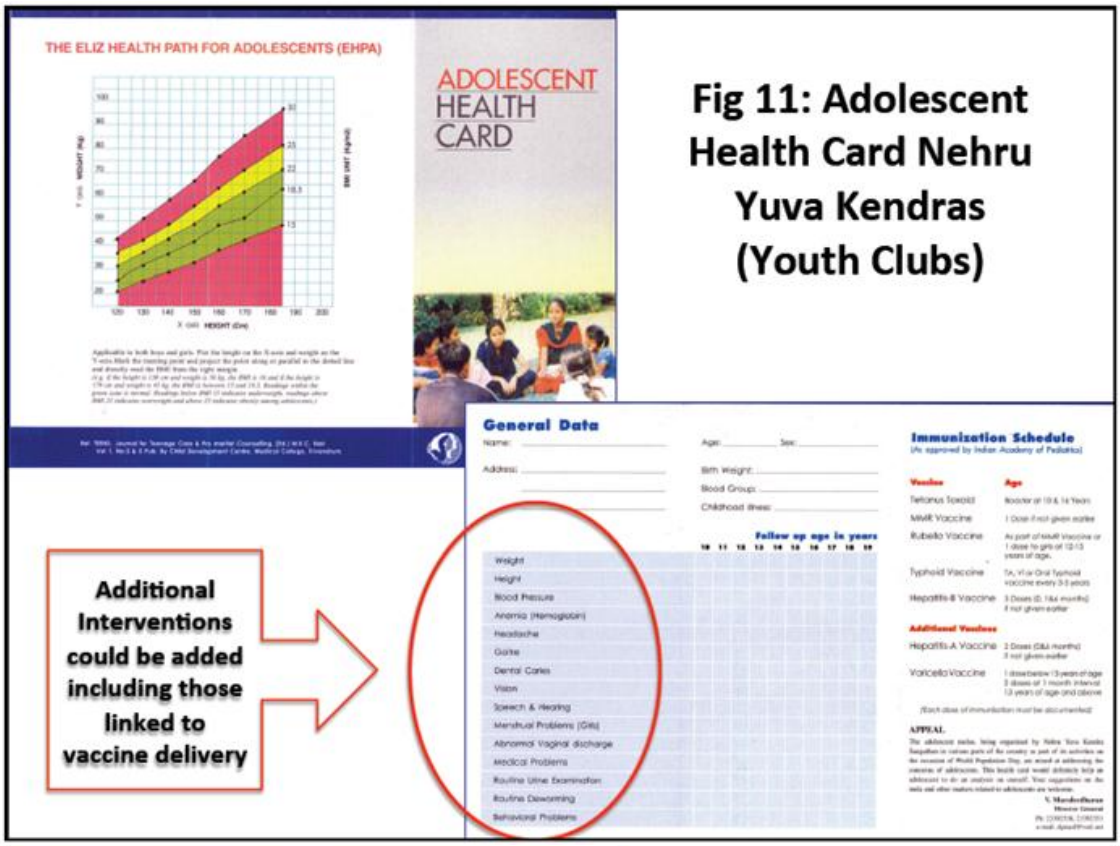


Fig 11: Adolescent Health Card Nehru Yuva Kendras (Youth Clubs)

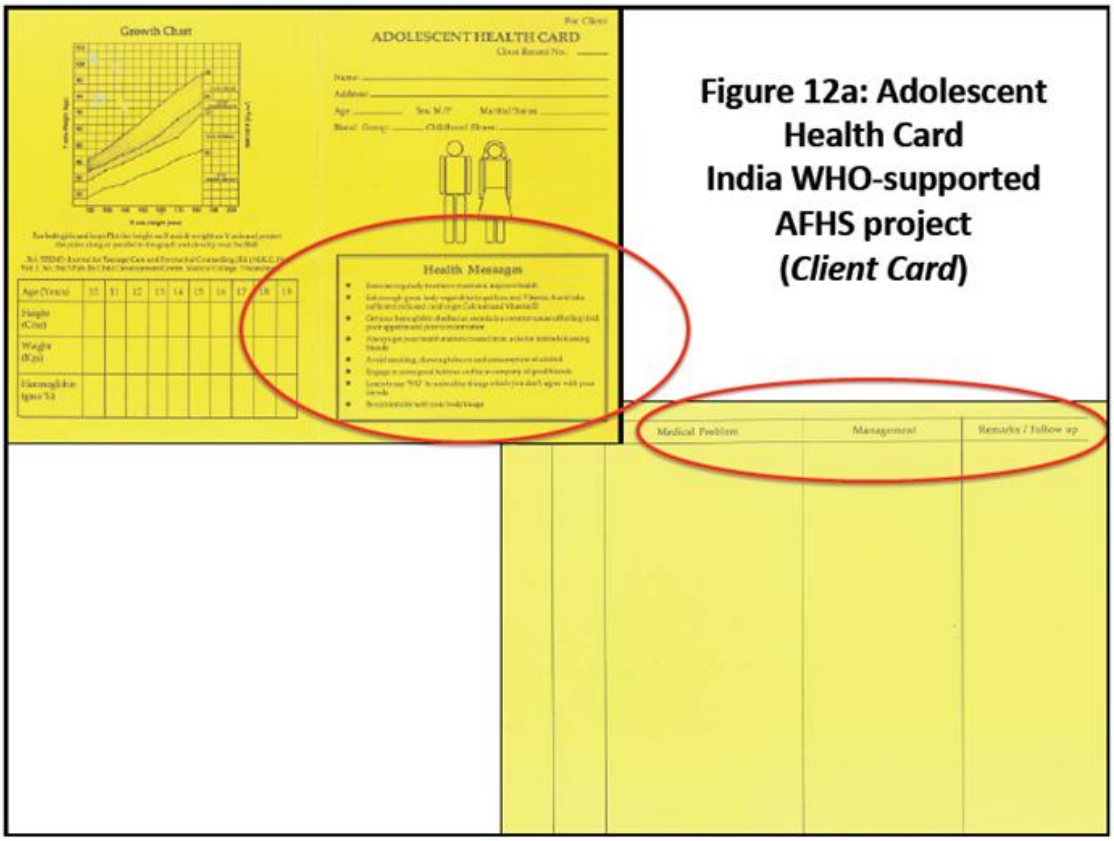


Figure 12a: Adolescent Health Card India WHO-supported AFHS project (*Client Card*)

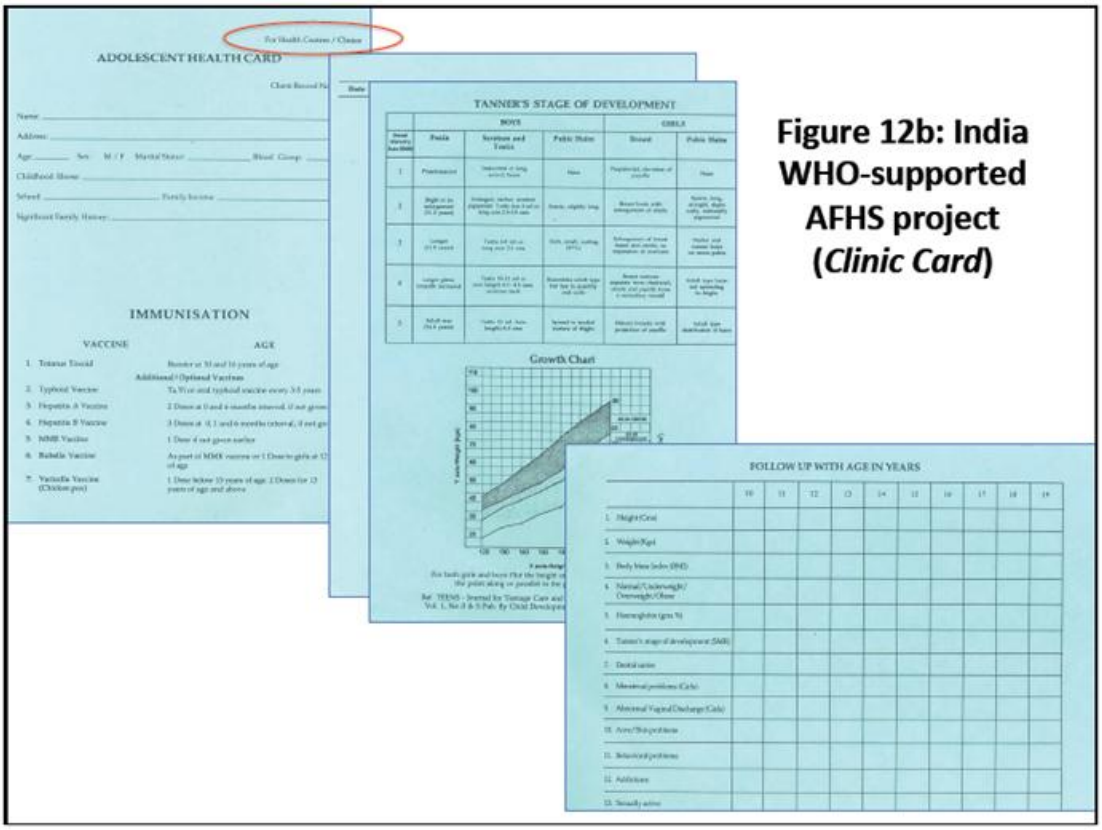


Figure 12b: India WHO-supported AFHS project (*Clinic Card*)

Fig 13: Cards for specific interventions: HPV vaccination (Uganda, India)

http://www.rho.org/HPV-vaccine-implementation.htm

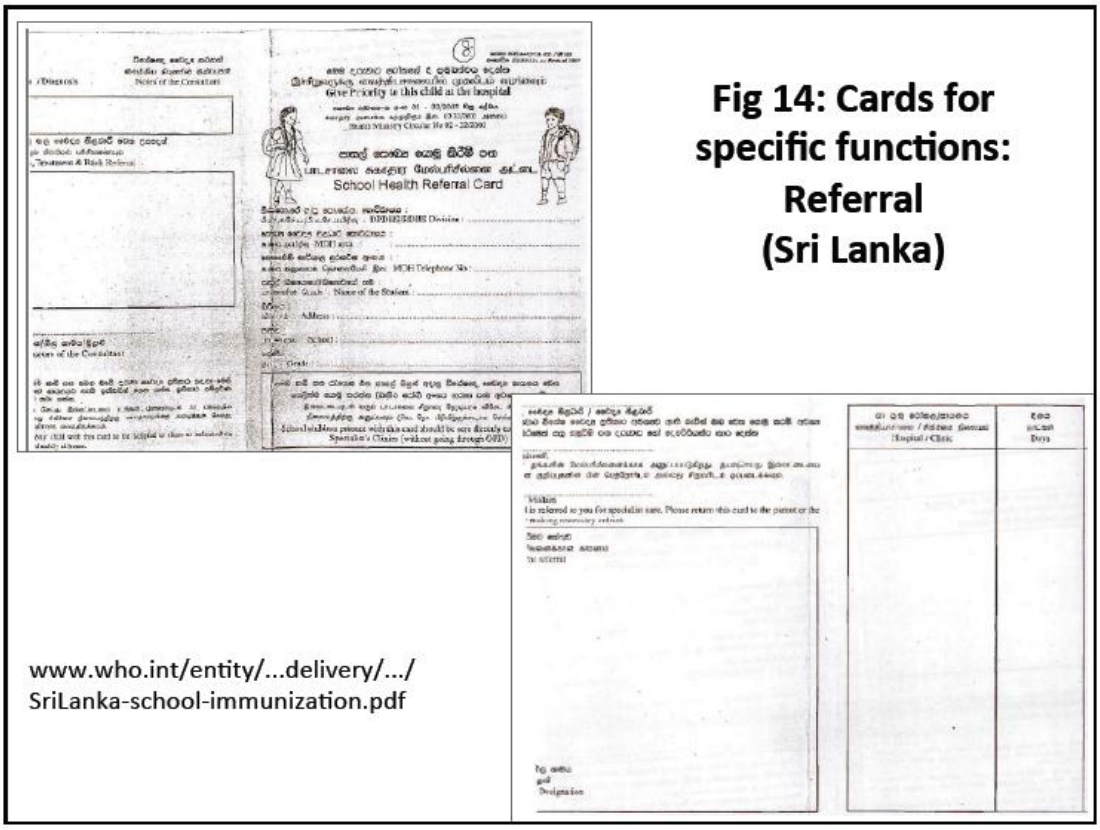


Fig 14: Cards for specific functions: Referral (Sri Lanka)

www.who.int/entity/...delivery/.../SriLanka-school-immunization.pdf

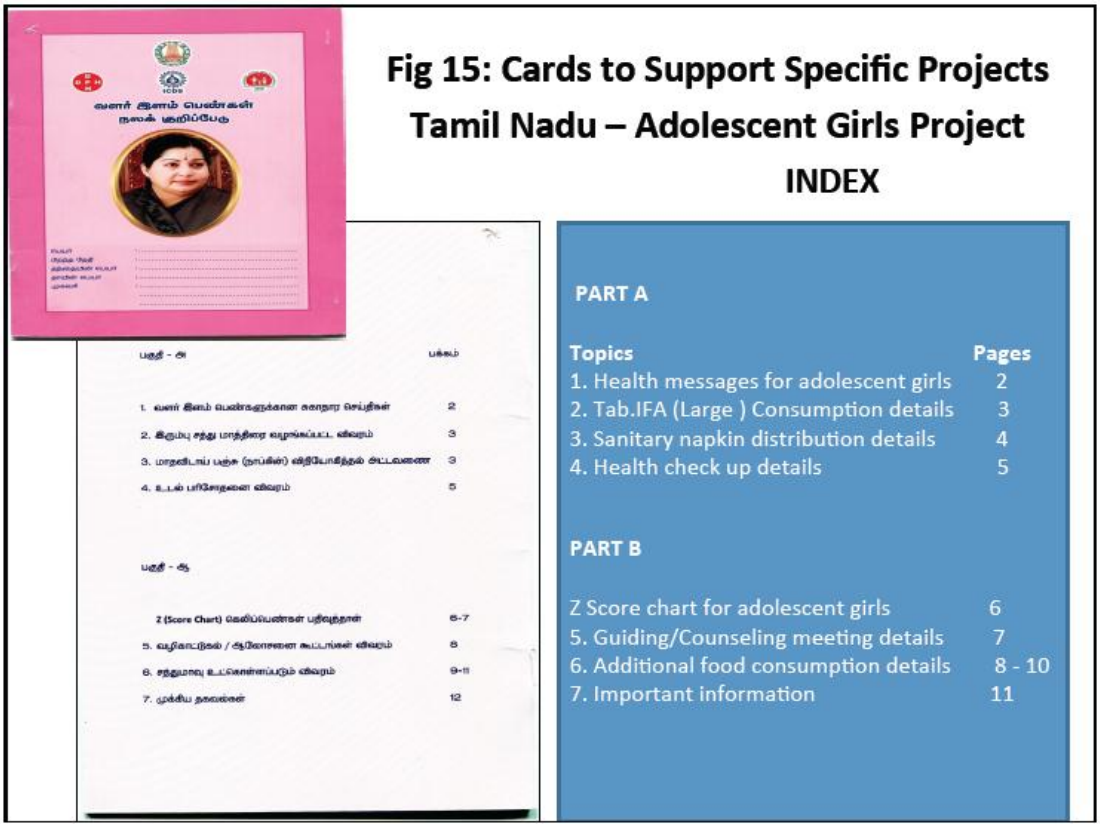


Fig 15: Cards to Support Specific Projects
Tamil Nadu – Adolescent Girls Project

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PART B

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http://www.msp.gub.uy/categoria_52_1_1.html

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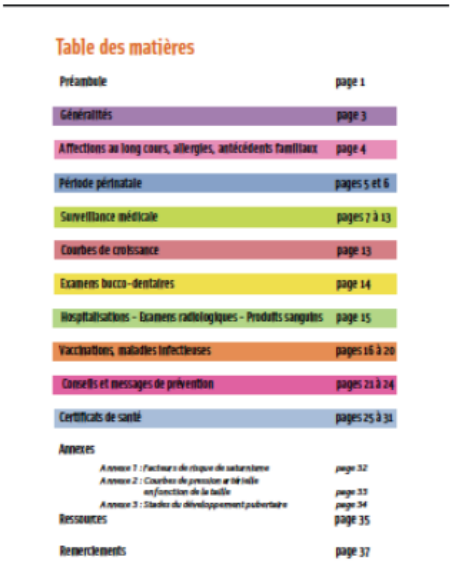
http://www.saude.ba.gov.br/index.php?option=com_content&view=article&id=142&catid=2&Itemid=17

Figure 18: France Carnet de Santé

A link between different health professionals; a record of health events of importance to the child and his/her family; a tool for health education



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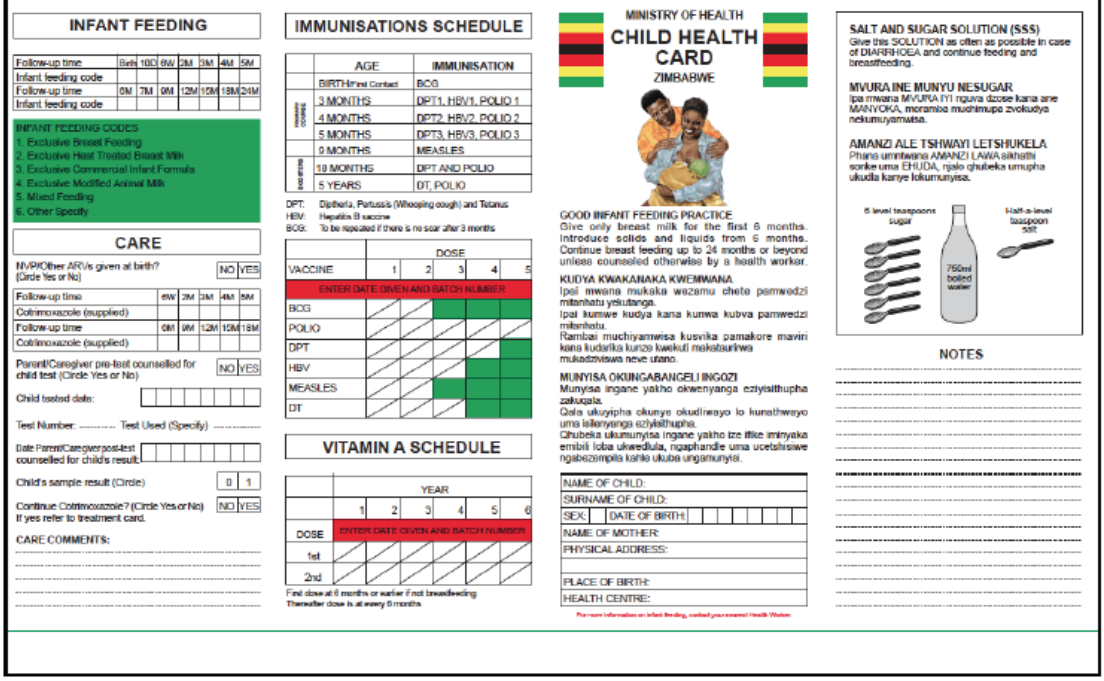
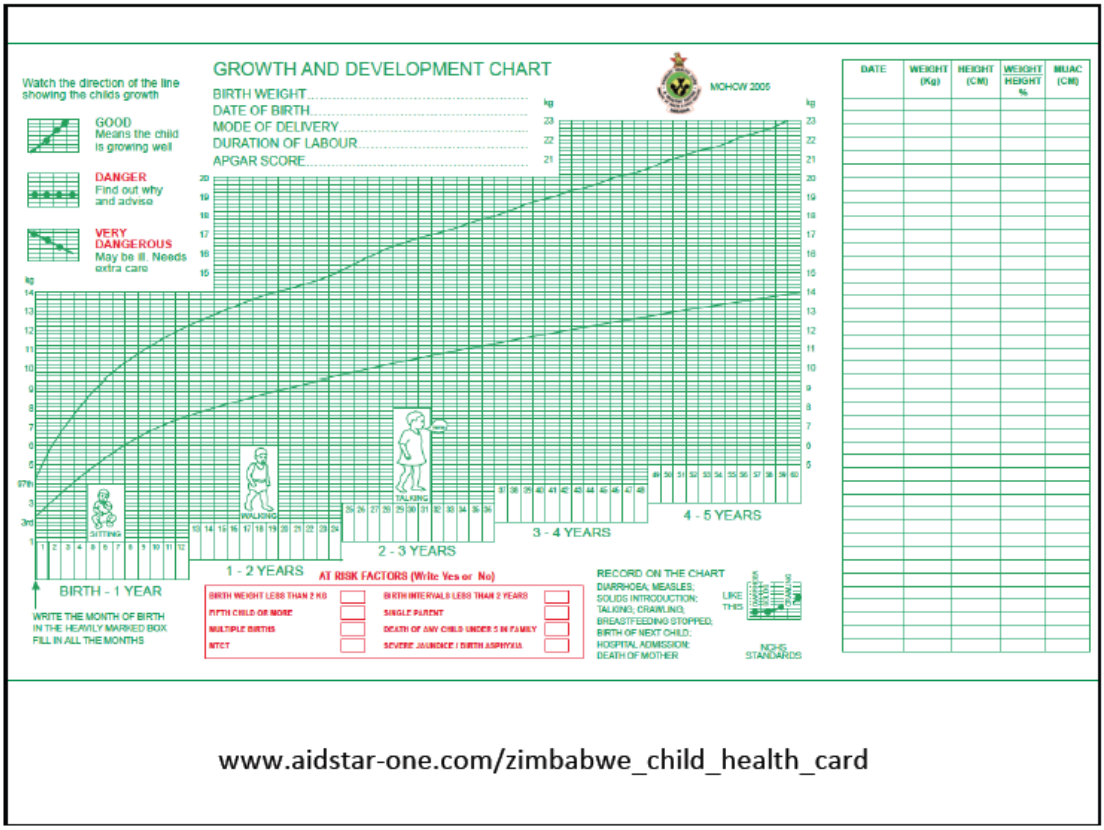
Annex 6: Example of a Child Health Card (Figure 19)

Figure 19: Zimbabwe Ministry of Health Child Health Card





www.aidstar-one.com/zimbabwe_child_health_card