# Developing and Addressing the Public Health Agenda for Psoriasis and Psoriatic Arthritis

**Centers for Disease Control and Prevention**
**National Center for Chronic Disease Prevention and Health Promotion**

This is a revised and condensed version of a report submitted on September 23, 2010 by SciMetrika under Contract # 200-2008-27889, Task Order 0006 and 0013**.**

*The findings and conclusions in this report are those of the author(s) and do not necessarily represent the views of the Centers for Disease Control and Prevention.*

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# 1 Introduction

### Developing the Public Health Agenda for Psoriasis and Psoriatic Arthritis

Public health is what we, as a society, do to assure the conditions for people to be healthy (Institute of Medicine, 1988). The three core functions of public health consist of assessment, policy development, and assurance (Institute of Medicine, 1988). In early 2010, the Arthritis Program of the Arthritis, Epilepsy, and Well-being Branch at the Centers for Disease Control and Prevention (CDC) received federal appropriations to begin developing a public health agenda addressing the assessment function for psoriasis and psoriatic arthritis. Psoriasis is an autoimmune disease which manifests on the skin and has been estimated to affect approximately five million people in the United States (NIH, 2009). Psoriatic arthritis is a condition which includes joint inflammation and skin lesions, though these may not occur at the same time. The onset of psoriasis generally occurs before psoriatic arthritis, though this is not always the case (NPF, 2010).

The first phase of this work ran from April to September 2010 and focused on meeting with expert consultants to identify and discuss key issues pertinent to the development of a public health agenda (Section 2.1) and reviewing the existing peer-reviewed, public health literature (Section 2.2). The results of the literature review and discussions with the expert consultants informed the summaries of current knowledge, needs, and gaps for each key issue (Section 2.3), as well as Public Health Agenda (Section 2.4) and Priorities for Public Health Research (Section 2.5).

### Addressing Psoriasis and Psoriatic Arthritis from a Public Health Perspective

The second phase of the project began in September 2010 and focused on refining the literature review on public health case definitions for psoriasis and psoriatic arthritis (Section 3.1); conducting epidemiologic analyses using existing data sources (Section 3.2); and carrying out a public health workshop with psoriasis and psoriatic arthritis experts (Section 3.3).

To ensure that the work met the highest quality standards, five experts in the fields of psoriasis, psoriatic arthritis, and public health provided subject matter expertise throughout the duration of the project. Based on their feedback, CDC revised the work so that it was most applicable to the field.

# 2 Developing a Public Health Agenda for Psoriasis and Psoriatic Arthritis

The project's first phase occurred from April to September 2010; the work included discussing key issues with experts (Sections 2.1 and 2.3), conducting a literature review (Sections 2.2 and 2.3), and developing a Public Health Agenda and Priorities for Public Health Research that could be undertaken as time, opportunity, and resources permit (Section 2.4).

## 2.1 *Expert Consultation*

CDC sought input from experts to identify and discuss issues pertinent to addressing these diseases from a public health perspective. The consultation consisted of psoriasis, psoriatic

arthritis, and public health experts from federal agencies, non-profit organizations, universities, hospitals, and clinics. Over the course of four teleconferences and an in-person meeting, the experts discussed the validity of existing data, identified needs and gaps, and provided suggestions for future research.

## Steering Committee

CDC established a Steering Committee to guide the efforts of the expert consultation. The committee included Dr. Charles Helmick (CDC), Dr. Joel Gelfand (University of Pennsylvania), Dr. Bruce Bebo, Jr. (National Psoriasis Foundation), and Dr. Jeffrey Sacks (CDC consultant).

## Summary of Meetings

From April to August 2010, four teleconferences and an in-person meeting were held with 9-16 experts per meeting (Table 1).

**Table 1: Meeting attendance**

| | Attendance | Expert Consultant Affiliations |
|---|---|---|
| Teleconference 1: Introduction to the Project | 14 experts | Boston University, CDC, Cleveland Clinic, Harvard University, National Psoriasis Foundation, National Institutes of Health, Northwestern University, University of Michigan, University of Pennsylvania, University of Rochester, University of Toronto |
| In-Person meeting: Discuss the Issues | 16 experts | American Academy of Dermatology, CDC, Cleveland Clinic, Harvard University, National Psoriasis Foundation, National Institutes of Health, Northwestern University, University of Pennsylvania, University of Utah |
| Teleconference 2: Burden and Disparities | 13 experts | CDC, Cleveland Clinic, Harvard University, National Psoriasis Foundation, National Institutes of Health, Seattle Rheumatology Associates, University of Pennsylvania, University of Rochester, University of Toronto, University of Utah |
| Teleconference 3: Case Definitions and Severity | 9 experts | CDC, Harvard University, National Psoriasis Foundation, Northwestern University, Seattle Rheumatology Associates, University of Michigan, University of Rochester, University of Toronto |
| Teleconference 4: Comorbidities and Natural History | 9 experts | CDC, Cleveland Clinic, Harvard University, National Psoriasis Foundation, University of Pennsylvania, University of Toronto, University of Utah |

### Teleconference 1: Introduction to the Project (April 30, 2010)

In anticipation of the in-person meeting, CDC held a one-hour introductory teleconference with the experts. CDC provided background information on the project and suggested a list of potential issues that could be addressed with the funding. Each expert identified which of the issues he/she believed to be the most important. Some of the experts added other items to this list. The most common were burden, case definitions, comorbidities, disparities, natural history, and severity.

### In-Person Meeting: Discussion about the Issues (May 7, 2010)

On May 7, 2010, CDC held a two-hour face-to-face meeting with the experts to consider the following for each of the six previously identified issues:

- Importance to public health
- Measurement
- Data sources
- Feasibility

The experts divided themselves into three groups, and each group discussed two issues: burden and disparities; natural history and comorbidities; and case definitions and severity. After deliberation, each group presented their prioritized list of topics to the full group (Table 2).

**Table 2: High priority topics identified by 2 or more experts**

| Issue | Topic | Number of votes |
|---|---|---|
| Burden and Disparities | Quality of Life | 4 |
| | Pediatric Burden | 2 |
| Natural History | Life expectancy/mortality | 4 |
| | Triggers/flares | 3 |
| | Tobacco's role in onset | 2 |
| | Pregnancy/childbearing | 2 |
| | Patterns of care | 2 |
| Comorbidities | Obesity/metabolic syndrome | 5 |
| | Major cardiovascular events | 4 |
| | Infection | 2 |
| Case definitions | Self-reporting | 8 |
| | Accuracy of diagnoses in medical/insurance databases | 8 |
| | Misdiagnosis | 3 |
| | Selection bias | 3 |
| Severity | Telescoping/episodic nature | 6 |
| | Lack of objective measurement | 5 |
| | Accounting for comorbidities | 5 |
| | Lack of databases tracking | 5 |
| | Need to add QOL | 2 |

## Teleconference 2: Burden and Disparities (August 6, 2010)

On August 6, 2010, CDC held a second teleconference to discuss burden and disparities associated with psoriasis and psoriatic arthritis. SciMetrika developed an executive summary and supplemental, detailed tables for the US literature for each of the following issues: prevalence, age of onset, health care utilization, employment/work, direct costs, indirect costs, health-related quality of life, and disparities. These documents were shared with the full group one week before the teleconference.

Two consultants provided feedback via e-mail in advance of the meeting, and their comments were incorporated into the discussion. A third expert e-mailed comments after the meeting, and his feedback was incorporated into the meeting summary.

During the teleconference, the experts suggested key articles and discussed the information presented in the executive summaries. At the end of the meeting, each expert stated his/her top two priorities.

Teleconference 3: Case Definitions and Severity (August 19, 2010)

On August 19, 2010, CDC held a teleconference to discuss case definitions and severity. The previous teleconference on burden and disparities made apparent the need for accurate and appropriate case definitions, therefore these two issues were chosen to be discussed before comorbidities and natural history.

The group discussed the validity of existing case definitions of psoriasis and psoriatic arthritis, as well as the accuracy of diagnoses by various types of physicians. The validity of severity measurements for psoriasis and psoriatic arthritis were also discussed, with a focus on their applicability on a population-based level.

At the end of the meeting, each expert provided his/her opinion regarding the most pertinent topics or research questions related to case definitions and severity.

Teleconference 4: Comorbidities and Natural History (August 30, 2010)

On August 30, 2010, CDC held a final teleconference with the expert consultants to address comorbidities and natural history. Comorbidities focused on major cardiovascular diseases and obesity, both of which were rated the most important during the in-person meeting (Table 2).

The group discussed the connectedness between the issues, such as the relationship between the psychosocial/quality of life aspects of psoriasis and obesity, as well as the relationship between cardiovascular diseases and obesity. A variety of potential data sets were discussed in terms of their feasibility for studying the natural history of psoriasis and/or psoriatic arthritis.

At the end of the teleconference, each participant stated his/her opinions regarding the most pertinent topics or research questions related to comorbidities and natural history.

## 2.2 *Literature Review Methods*

After the in-person meeting, a systematic literature review was conducted to better understand what was currently known about psoriasis and psoriatic arthritis and identify gaps in the public health knowledge. The results of this review were shared with the expert consultants and guided the teleconference discussions.

### Inclusion and Exclusion Criteria

Articles were required to address one or more of the following:

- Burden (prevalence, age of onset, direct costs, indirect costs, health care utilization, employment/work burden, health-related quality of life)
- Case definitions
- Comorbidities (major cardiovascular diseases, obesity)
- Disparities (age, gender, racial/ethnic)
- Natural history
- Severity

Articles that pertained to the pediatric population, letters to the editor, and articles that discussed measurement issues or instrument validation were included. Case reports, articles that did not address any of the above topics (e.g., treatment), animal studies, and purely clinical studies were excluded from this review.

### PubMed Search

The search included articles published in English from January 1, 1990 to May 17, 2010 and was limited to titles/abstracts only. In total, 524 hits were retrieved. The syntax can be found in Table 3.

**Table 3: PubMed search syntax**

| |
|---|
| ("psoriasis" OR "psoriatic arthritis") AND ("burden" OR "cardiovascular disease" OR "case definition" OR "natural history" OR "pediatric" OR "health-related quality of life" OR "obesity" OR ("prevalence" AND "estimate") OR ("severity" AND "measurement")) |

#### Relevance Classifications and Quality Assurance Procedures

A two-phase relevance classification and quality assurance procedure was performed. In the first phase, a primary reviewer read all 524 abstracts and classified each as potentially relevant (PR) or not relevant (NR). Then, an independent, secondary reviewer read a 25% random subsample of the 524 abstracts (i.e., 131 abstracts) and classified each as PR or NR. Both the primary and secondary reviewers' classifications were sent to a third reviewer who reconciled any discrepancies. Phase I quality assurance (QA) revealed that two articles had been classified by the primary reviewer as NR when in fact they were PR. This yielded a false negative rate of 1.53%. In total, 266 articles were rated PR.

In the second phase, the primary reviewer read the full-texts of all PR articles and classified each as relevant (R) or not relevant (NR). Then, the same secondary reviewer read a 25% random subsample of the 266 PR articles (i.e., 66 articles) and classified each as R or NR. Both the primary and secondary reviewers' classifications were sent to a third reviewer who reconciled any discrepancies. Phase II QA determined that none of the articles had been classified by the primary reviewer as NR when in fact they were R. This yielded a false negative rate of 0%. Of 266 PR articles, 219 were considered R.

During both QA phases, the secondary reviewer was blinded to the classifications of the primary reviewer.

### Supplemental Searches

To ensure completeness of the review, the following supplemental searches were also conducted.

#### Suggested Literature from Expert Consultants

Throughout the duration of the project, the expert consultants shared any additional literature they considered pertinent to addressing psoriasis and/or psoriatic arthritis from a public health

perspective. Of the 39 recommended articles, 10 were retrieved in the PubMed search and 25 were considered relevant to the review (Table 4).

National Psoriasis Foundation Literature Catalog

One of the expert consultants provided a compilation of citations and abstracts related to psoriasis and psoriatic arthritis which was current through 2009 ("NPF Catalog"). This literature catalog addressed burden (economic and quality of life), comorbidities, epidemiology, the pediatric population, and severity. Of 96 PR abstracts, 35 were retrieved through the PubMed search and/or the suggested literature from expert consultants. Of the 61 articles which had not been retrieved, 27 were considered relevant (Table 4).

Review of Reference Lists

Finally, two reference list searches were conducted. The first search reviewed the reference lists of all key articles suggested by the expert consultants. Of these, 44 references were identified which were not included in either the PubMed search or the NPF catalog. Of these 44 hits, 30 were rated PR and 23 were considered relevant to the review (Table 4).

The second search reviewed the reference lists of the most recent psoriasis and psoriatic arthritis review articles from the PubMed search. This search retrieved four additional references which were considered relevant to the review (Table 4).

### Summary of Relevant Literature

The combined PubMed and supplemental literature searches resulted in 298 relevant articles. A breakdown of the initial hits and two-phase relevance classifications can be found in Table 4.

**Table 4: Literature review relevance classifications**

| Database | Total Hits | Hits after cross-check | Phase I Relevance (PR) | Phase II Relevance (R) |
|---|---|---|---|---|
| PubMed syntax | 524 | N/A* | 266 | 219 |
| Suggested Lit from Experts | 39 | 10 | 29 | 25 |
| NPF catalog | 96 | 35 | 31 | 27 |
| Reference Lists | | | | |
| Suggested Lit from Experts | 44 | N/A** | 30 | 23 |
| Psoriasis Review Article (2010) | 1 | N/A** | 1 | 1 |
| Psoriatic Arthritis Review Article (2009) | 3 | N/A** | 3 | 3 |
| **Total** | **707** | | **360** | **298** |

*PubMed search was used to cross-check supplemental searches.

**Reference lists were cross-checked before being added to the total hits column.

### Article Abstraction

To ensure all pertinent information was extracted from each article, a data abstraction form was created in Microsoft Excel to catalog this information. The form included a summary of the study methodology, results, conclusions and recommendations proposed by the authors.

## 2.3 *Summary of Current Knowledge, Needs, and Gaps*

Of the 298 articles included in this review, 198 were original research, seven were commentaries, and 93 were reviews. The reviews and commentaries were used for background information and in the formulation of agenda items and priorities.

Sixty-eight of the original research articles were US-based or international studies that included US populations ("*US articles*"), and 130 articles studied populations outside of the US ("*non-US articles*"). Most of the non-US literature originated in Europe (n=76) and Canada (n=27). In the US literature, psoriatic arthritis was the least studied (Table 5).

**Table 5: Number of articles that addressed psoriasis and/or psoriatic arthritis**

| Disease | US articles | non-US articles | Total |
|---|---|---|---|
| Psoriasis only | 31 | 52 | 83 |
| Psoriatic arthritis only | 11 | 52 | 63 |
| Both psoriasis and psoriatic arthritis | 26 | 26 | 52 |
| **Total** | **68** | **130** | **198** |

From 1990 to May 2010, only 14 population-based studies were conducted on psoriasis and/or psoriatic arthritis in the US. Almost half of the literature retrieved in the search was carried out within clinic-based populations (Table 6).

**Table 6: Number of US articles for each study type, stratified by disease studied**

| | Psoriasis only | Psoriatic arthritis only | Psoriasis and psoriatic arthritis | Total* |
|---|---|---|---|---|
| Population-Based | 10 | 2 | 2 | 14 |
| Clinic-Based | 17 | 5 | 11 | 33 |
| Insurer Claims | 0 | 1 | 7 | 8 |
| Registry-Based | 1 | 1 | 3 | 5 |
| Other | 1 | 2 | 5 | 8 |
| **Total** | **29** | **11** | **28** | **68** |

As CDC was most interested in US-based research, the sections which follow are based on the 68 US articles, as well as feedback from the expert consultants during the teleconferences that followed the in-person meeting.

### 2.3.1 Burden: Prevalence

The following summarizes the US-based literature for prevalence (Tables 7-8), examines the validity of the data, and identifies needs, gaps, and databases used to study the issue.

**Table 7: Prevalence – psoriasis research**

| Article Type | n | Data Source |
|---|---|---|
| Population-Based | 7 | 2003-2004 National Health and Nutrition Examination Survey (NHANES) (n=1)<br>2001 National Psoriasis Foundation-commissioned survey (n=2)<br>1996 National Health Interview Survey (NHIS) (n=1)<br>1991 Psoriasis Quality of Life survey (n=1) |

| | | |
|---|---|---|
| | | 1982-1991 Rochester Epidemiology Project (n=1)<br>1971-1974 Health and Nutrition examination Survey (HANES) I and 1993-1995 United Health Care/Diversified Pharmaceutical Services database (n=1) |
| Clinic-Based | 0 | N/A |
| Insurer-Claims | 4 | 2001-2002 IMS Health Integrated Administrative Claims (n=2)<br>2001-2002 unspecified database (n=1)<br>1996-2000 MedStat (n=1) |
| Internet-Based | 0 | N/A |
| Registry-Based | 1 | 2003-2005 National Psoriasis Foundation survey |

**Table 8: Prevalence – psoriatic arthritis research**

| Article Type | n | Data Source |
|---|---|---|
| Population-Based | 2 | 2001 National Psoriasis Foundation-commissioned survey (n=1)<br>1970-1999 Rochester Epidemiology Project (n=1) |
| Clinic-Based | 10 | Various clinic sites across the US |
| Insurer-Claims | 5 | 2003 MedStat MarketScan (n=1)<br>2001-2002 unspecified databases (n=1)<br>2001-2002 IMS Health Integrated Administrative Claims (n=1)<br>2001-2002 PharMetrics Patient-Centric Database (n=1)<br>1996-2000 MedStat (n=1) |
| Internet-Based | 3 | John's Hopkins survey |
| Registry-Based | 3 | 2003-2005 National Psoriasis Foundation survey (n=1)<br>1998 survey of National Psoriasis Foundation contacts (n=1)<br>1996-1998 Veterans Integrated Service Network (n=1) |

## Validity of the Data

Psoriasis estimates in the population-based literature seem valid and continue to support that psoriasis can be found in 1-3% of the population. With only one nationally-representative, population-based study conducted nearly a decade ago on psoriatic arthritis, there is currently not enough data available for reliable prevalence estimates within the general population or the psoriatic population.

## Needs and Gaps

- Knowledge regarding the validity of self-reported psoriasis and psoriatic arthritis data
- More recent prevalence estimates to compare with those using the 1996 NHIS or 2003-2004 NHANES studies
- More research to estimate the prevalence of psoriatic arthritis within the general population and within the psoriasis population
    - Examine relationship with health insurance coverage (or access to health care)
    - Examine potential for NHANES to provide a comprehensive approach to addressing this gap from a population-based perspective
    - Timing of psoriatic arthritis diagnosis
- Prevalence estimates at various levels of psoriasis and psoriatic arthritis severity
    - Extent of skin involvement, involvement of sensitive areas known to be associated with a higher degree of morbidity and disability

    - Prevalence of mild, moderate, and severe psoriasis and how they relate to comorbidities and treatments
    - Prevalence of mild, moderate, and severe psoriatic arthritis and how they relate to comorbidities and treatments
- Accurate and reliable public health case definitions based on population-based data
    - Clinically-based case definitions can be distorted by selection and publication bias

Databases Used

- Health and Nutrition Examination Survey I (HANES)
- Insurer claims (IMS Health Integrated Administrative Claims, MarketScan, PharMetrics Patient-Centric Database, United Health Care/Diversified Pharmaceutical Services)
- National Health Interview Survey (NHIS)
- National Health and Nutrition Examination Survey (NHANES)
- National Psoriasis Foundation surveys
- Rochester Epidemiology Project
- Psoriasis Quality of Life study

### 2.3.2 Burden: Age of Onset

The following summarizes the US-based literature for age of onset (Tables 9-10), examines the validity of the data, and identifies needs, gaps, and databases used to study the issue.

**Table 9: Age of onset – psoriasis research**

| Article Type | n | Data Source |
|---|---|---|
| Population-Based | 1 | 1996 Psoriasis Quality of Life study |
| Clinic-Based | 5 | Various clinic sites across the US |
| Insurer-Claims | 0 | N/A |
| Internet-Based | 1 | 2005 John's Hopkins study |
| Registry-Based | 3 | 2005 National Psoriasis Foundation survey (n=1)<br>2003-2005 National Psoriasis Foundation survey (n=1)<br>1998 survey of National Psoriasis Foundation contacts (n=1) |

**Table 10: Age of onset – psoriatic arthritis research**

| Article Type | n | Data Source |
|---|---|---|
| Population-Based | 1 | 1982-1991 Rochester Epidemiology Project |
| Clinic-Based | 1 | Massachusetts clinic |
| Insurer-Claims | 0 | N/A |
| Internet-Based | 0 | N/A |
| Registry-Based | 1 | 2005 National Psoriasis Foundation survey |

Validity of the Data

With only one population-based study estimating the age of psoriasis onset and one sub-national population-based study estimating the psoriatic arthritis age of onset, there is not enough research to assess validity of the data. Determining psoriasis onset is thought to be more reliable because people usually remember when lesions appear on their skin. Psoriatic arthritis is harder because people may not recognize the problem until deformities have occurred. Recall bias in

self-reported onset after age 18 years may also be a concern, and research has shown that reported onset often occurs in 5-year breaks (e.g., 20 years, 25 years, 30 years, etc.).

Needs and Gaps

- Updating existing studies with more recent data
- Survey instruments designed to reduce recall bias for age of onset

Databases Used

- National Psoriasis Foundation surveys
- Psoriasis Quality of Life Study
- Rochester Epidemiology Project
- John's Hopkins internet-based study

### 2.3.3 Burden: Costs (direct and indirect)

The following summarizes the US-based literature for direct and/or indirect costs (Tables 11-12), examines the validity of the data, and identifies needs, gaps, and databases used to study the issue.

**Table 11: Direct and/or indirect costs – psoriasis research**

| Article Type | n | Data Source |
|---|---|---|
| Population-Based | 2 | 1996 NHIS (n=1)<br>1990 NHDS, 1993 Medicare Part A Hospitalizations, 1993-1995 UHC/DPS database, 1993 Medicare Part A Inpatient Physician Services, 1991 and 1993 NAMCS, 1992 and 1993 NHAMCS-OV, 1993 Medicare Part B Outpatient Physician Services, 1996 NDTI (n=1) |
| Clinic-Based | 0 | N/A |
| Insurer-Claims | 4 | 1998-2005 unspecified databases (n=1)<br>2003 MedStat MarketScan (n=1)<br>2000 MarketScan and Medicare Supplemental Coordination of Benefits (n=1)<br>1996-2000 MedStat (n=1) |
| Internet-Based | 1 | 2005 John's Hopkins Survey (n=1) |
| Registry-Based | 2 | 2005 National Psoriasis Foundation Survey (n=1)<br>1998 survey of National Psoriasis Foundation contacts (n=1) |

**Table 12: Direct and/or indirect costs – psoriatic arthritis research**

| Article Type | n | Data Source |
|---|---|---|
| Population-Based | 1 | 1990 NHDS, 1993 Medicare Part A Hospitalizations, 1993-1995 UHC/DPS database, 1993 Medicare Part A Inpatient Physician Services, 1991 and 1993 NAMCS, 1992 and 1993 NHAMCS-OV, 1993 Medicare Part B Outpatient Physician Services, 1996 National Disease Therapeutic Index |
| Clinic-Based | 0 | N/A |
| Insurer-Claims | 0 | N/A |
| Internet-Based | 1 | 2005 John's Hopkins Survey (n=1) |
| Registry-Based | 1 | 2005 National Psoriasis Foundation Survey (n=1) |

Validity of the Data

The most recent data on direct costs from the population-based studies is from the early 1990s and may no longer be valid, particularly given the increasing costs of health care in the US. Currently, cost of illness studies use econometric models that adjust for a variety of demographic and comorbid factors and try to count each dollar just once (rather than multiple times, as has been done in previous cost-of-illness studies).

Little research has been conducted on indirect costs and what has been done is outdated. In the US, only one population-based study has evaluated the indirect costs associated with psoriasis, and none have been done for psoriatic arthritis.

Needs and Gaps

- Accurate and reliable case definitions to develop accurate cost estimates
- More current cost estimates, with direct comparison of psoriasis and psoriatic arthritis
- More research on how costs of psoriasis and psoriatic arthritis are affected by severity
- More population-based research to validate the findings in the insurer claims, internet-based, and registry-based studies

Databases Used

- Health and Nutrition Examination Survey (HANES I)
- Insurer claims (IMS Health Integrated Administrative Claims, MarketScan, United Health Care/Diversified Pharmaceutical Services)
- National Health Interview Survey (NHIS)
- National Hospital Discharge Survey (NHDS)
- Medicare Part A Hospitalizations and Inpatient Services
- Medicare Part B Outpatient Physician Services
- National Ambulatory Medical Care Survey (NAMCS)
- National Disease Therapeutic Index (NDTI)
- National Hospital Ambulatory Medical Care Survey (NHAMCS)-OV
- National Psoriasis Foundation surveys
- Telephone/internet surveys

### 2.3.4 Burden: Health Care Utilization

The following summarizes the US-based literature for health care utilization (Tables 13-14), examines the validity of the data, and identifies needs, gaps, and databases used to study the issue.

**Table 13: Health care utilization – psoriasis research**

| Article Type | n | Data Source |
|---|---|---|
| Population-Based | 2 | 2001 National Psoriasis Foundation-commissioned survey (n=2) |
| Clinic-Based | 0 | N/A |
| Insurer-Claims | 3 | 2003 MedStat MarketScan (n=1)<br>1996-2000 MedStat (n=1)<br>1996-2000 MarketScan and Medicare Supplemental COB (n=1) |
| Internet-Based | 0 | N/A |

| | | |
|---|---|---|
| Registry-Based | 0 | N/A |

**Table 14: Health care utilization – psoriatic arthritis research**

| Article Type | n | Data Source |
|---|---|---|
| Population-Based | 0 | N/A |
| Clinic-Based | 0 | N/A |
| Insurer-Claims | 0 | N/A |
| Internet-Based | 0 | N/A |
| Registry-Based | 1 | 1996-1998 Veterans Integrated Service Network |

Validity of the Data

Although two articles have explored health care utilization among individuals with psoriasis, they both used the same data set. No research has focused on those with psoriatic arthritis. A major concern for health care utilization research pertains to missed data from patients who received care but whose medical records did not contain an ICD-9 code for psoriasis or psoriatic arthritis.

Needs and Gaps

- Population-based data to validate findings of insurer claims studies for psoriasis
- Research on psoriatic arthritis

Databases Used

- Insurer claims (MarketScan, Medicare Supplemental Coordination of Benefits)
- National Psoriasis Foundation surveys
- Veterans Integrated Service Network

### 2.3.5 Burden: Employment/Work

The following summarizes the US-based literature for employment and work burden (Tables 15-16), examines the validity of the data, and identifies needs, gaps, and databases used to study the issue.

**Table 15: Employment/work burden – psoriasis research**

| Article Type | n | Data Source |
|---|---|---|
| Population-Based | 1 | 2001 National Psoriasis Foundation-commissioned survey |
| Clinic-Based | 3 | Various clinic sites across the US |
| Insurer-Claims | 0 | N/A |
| Internet-Based | 1 | 2005 John's Hopkins survey |
| Registry-Based | 4 | 2005 National Psoriasis Foundation survey (n=1)<br>2003-2005 National Psoriasis Foundation survey (n=2)<br>1998 survey of National Psoriasis Foundation contacts (n=1) |
| Other | 2 | 1 abstract and 1 study conducted by NFO |

**Table 16: Employment/work burden – psoriatic arthritis research**

| Article Type | n | Data Source |
|---|---|---|
| Population-Based | 0 | N/A |
| Clinic-Based | 0 | N/A |
| Insurer-Claims | 0 | N/A |
| Internet-Based | 1 | 2005 John's Hopkins survey |
| Registry-Based | 2 | 2005 National Psoriasis Foundation survey (n=1)<br>2003-2005 National Psoriasis Foundation survey (n=1) |

Validity of the Data

US-based research has been primarily restricted to subjects with known psoriasis and/or psoriatic arthritis. With only one population-based study of psoriasis, there is not currently enough data available to evaluate the validity of the estimates. No population-based research has examined the impact of psoriatic arthritis on employment or work burden.

Needs and Gaps

- Population-based data addressing this issue for psoriasis and psoriatic arthritis
- Improved understanding the impact of psoriasis on productivity while at work

Databases Used

- Internet survey
- National Psoriasis Foundation-commissioned survey
- National Psoriasis Foundation surveys

### 2.3.6 Burden: Health-Related Quality of Life

The following summarizes the US-based literature for health-related quality of life (HRQOL) (Tables 17-18), examines the validity of the data, and identifies needs, gaps, databases, and tools used to study the issue.

**Table 17: Health-related quality of life – psoriasis research**

| Article Type | n | Data Source |
|---|---|---|
| Population-Based | 6 | 2003-2004 NHANES (n=1)<br>2001 National Psoriasis Foundation-commissioned survey (n=3)<br>1996 NHIS (n=1)<br>1991 Ps Quality of Life survey (n=1) |
| Clinic-Based | 14 | Various clinic sites across the US |
| Insurer-Claims | 0 | N/A |
| Internet-Based | 3 | 2005 John's Hopkins survey (n=3) |
| Registry-Based | 3 | 2005 National Psoriasis Foundation survey (n=1)<br>2003-2005 National Psoriasis Foundation survey (n=1)<br>1998 survey of National Psoriasis Foundation contacts (n=1) |
| Other | 1 | non-US study compared their results with a study conducted by the University of Southern California |

**Table 18: Health-related quality of life – psoriatic arthritis research**

| Article Type | n | Data Source |
|---|---|---|
| Population-Based | 1 | 2001 National Psoriasis Foundation-commissioned survey |
| Clinic-Based | 2 | Various clinic sites across the US |
| Insurer-Claims | 0 | N/A |
| Internet-Based | 0 | N/A |
| Registry-Based | 3 | 2005 National Psoriasis Foundation survey (n=1)<br>2003-2005 National Psoriasis Foundation survey (n=1)<br>1998 survey of National Psoriasis Foundation contacts (n=1) |

## Validity of the Data

SF-36, DLQI, PsQOL and PsAQOL are the more common HRQOL instruments; however, the lack of understanding regarding the validity of self-reported psoriasis and psoriatic arthritis prevents interpretation of the few studies that exist. PDI was developed in the UK and is not widely used. PsQOL and PsAQOL are not ideal because they are proprietary and would require translation from British English to American English. The SF-36 does not capture domains of skin disease and probably will not capture functional impairment. Psoriatic arthritis is often evaluated in terms of functional impairment.

## Needs and Gaps

- Identify the most appropriate HRQOL measure(s) for psoriasis and psoriatic arthritis
- Research in psoriasis and psoriatic arthritis populations to validate current estimates
- More uniform measurements of HRQOL so that studies may be compared
- More research on age, gender, and race/ethnic disparities in HRQOL
- More research examining the validity of HRQOL measures from a population-based perspective
- More research on the relationship between severity and HRQOL

## Databases Used

- John's Hopkins internet-based survey
- National Health and Interview Survey (NHIS)
- National Health and Nutrition Examination Survey (NHANES)
- National Psoriasis Foundation surveys
- National Psoriasis Foundation-commissioned survey
- Psoriasis Quality of Life survey

## Tools Used

- Dermatology Life Quality Index (DLQI)
- Euro-QoL 5D (EQ-5D)
- Global question (rate on scale of 1-10)
- Impact of Psoriasis (IPSO) questionnaire
- National Psoriasis Foundation itch scale

- Psoriasis Disability Index (PDI)
- Psoriasis Quality of Life 12 (PQOL-12) (Koo Menter Psoriasis Instrument)
- Psoriasis Symptom Assessment scale
- Short Form Health Survey Questionnaire (SF-36)
- Satisfaction with Life Scale (SWLS)
- Willingness to Pay (WTP) model
- Visual Analog Scale (VAS)

### 2.3.7 Disparities

The following summarizes the US-based literature for age, gender, and racial/ethnic disparities (Tables 19-20), examines the validity of the data, and identifies needs, gaps, and databases used to study the issue.

**Table 19: Disparities – psoriasis research**

| Article Type | n | Data Source |
|---|---|---|
| Population-Based | 5 | 2003-2004 NHANES (n=1)<br>2001 National Psoriasis Foundation-commissioned survey (n=2)<br>1991 Psoriasis Quality of Life study (n=1)<br>1971-1974 HANES I and 1993-1995 UHC/DPS database (n=1) |
| Clinic-Based | 11 | Various clinic sites across the US |
| Insurer-Claims | 2 | 2001-2002 IMS Health Integrated Administrative Claims (n=2) |
| Internet-Based | 1 | 2005 John's Hopkins Survey |
| Registry-Based | 1 | 2005 National Psoriasis Foundation survey |

**Table 20: Disparities – psoriatic arthritis research**

| Article Type | n | Data Source |
|---|---|---|
| Population-Based | 2 | 2001 National Psoriasis Foundation-commissioned survey (n=1)<br>1970-1999 Rochester Epidemiology Project (n=1) |
| Clinic-Based | 2 | Various clinic sites across the US |
| Insurer-Claims | 1 | 2001-2002 IMS Health Integrated Administrative Claims |
| Internet-Based | 0 | N/A |
| Registry-Based | 1 | 2005 National Psoriasis Foundation survey |

Validity of the Data

Although some studies have noted age, gender, and racial/ethnic disparities, there is not enough research to evaluate the validity of this data.

Needs and Gaps

- More population-based research on psoriasis and psoriatic arthritis disparities

Databases Used

- Health and Nutrition Examination Survey I (HANES I)
- Insurer claims (IMS Health Integrated Administrative Claims, United Health Care/Diversified Pharmaceutical Services)

- National Health and Nutrition Examination Survey (NHANES)
- National Psoriasis Foundation surveys
- Rochester Epidemiology Project
- Psoriasis Quality of Life study

### 2.3.8 Case Definitions

The following summarizes the US-based literature for case definitions (Tables 21-22), examines the validity of the data, and identifies needs, gaps, and databases used to study the issue.

**Table 21: Case definitions – psoriasis research**

| Article Type | n | Data Source |
|---|---|---|
| Population-Based | 1 | 2003-2004 NHANES |
| Clinic-Based | 0 | N/A |
| Insurer-Claims | 0 | N/A |
| Internet-Based | 3 | 2005 John's Hopkins Survey (n=3) |
| Registry-Based | 1 | 2005 National Psoriasis Foundation survey |

**Table 22: Case definitions – psoriatic arthritis research**

| Article Type | n | Data Source |
|---|---|---|
| Population-Based | 0 | N/A |
| Clinic-Based | 3 | Various clinic sites across the US |
| Insurer-Claims | 0 | N/A |
| Internet-Based | 4 | 2005 John's Hopkins Survey (n=3)<br>Survey of physicians (n=1) |
| Registry-Based | 1 | 2005 National Psoriasis Foundation survey |
| Other | 1 | Core set of domains for psoriatic arthritis |

Validity of the Data

Research on the validity of psoriasis and psoriatic arthritis case definitions is lacking in the US literature. Only one population-based study examined case definitions of psoriasis; none of the psoriatic arthritis literature addressed this issue.

Needs and Gaps

- Population-based research on the adequacy of existing case definitions
- Accuracy of psoriasis diagnosis by non-dermatologists
- Accuracy of self-reported physician diagnosis
- Increased awareness of psoriatic arthritis, particularly among dermatologists
- Accuracy of Toronto PsA Screen (ToPAS) in the US

Databases Used

- National Health and Nutrition Examination Survey (NHANES)
- National Psoriasis Foundation surveys
- John's Hopkins internet-based survey

### 2.3.9 Severity

The following is a summary of the US-based literature for severity (Tables 23-24), followed by an examination of the validity of the data, needs and gaps, and databases and tools used to study the issue.

**Table 23: Severity – psoriasis research**

| Article Type | n | Data Source |
|---|---|---|
| Population-Based | 7 | 2003-2004 NHANES (n=1)<br>2001 National Psoriasis Foundation-commissioned survey (n=5)<br>1991 Psoriasis Quality of Life study (n=1) |
| Clinic-Based | 23 | Various clinic sites across the US |
| Insurer-Claims | 3 | 2003 MedStat MarketScan (n=1)<br>2001-2002 IMS Health Integrated Administrative Claims and MarketScan (n=1)<br>1996-2000 MedStat (n=1) |
| Internet-Based | 3 | 2005 John's Hopkins survey |
| Registry-Based | 4 | 2005 National Psoriasis Foundation survey (n=1)<br>2003-2005 National Psoriasis Foundation survey (n=2)<br>1998 survey of National Psoriasis Foundation contacts (1 article) |
| Other | 1 | NFO survey |

**Table 24: Severity – psoriatic arthritis research**

| Article Type | n | Data Source |
|---|---|---|
| Population-Based | 1 | 2001 National Psoriasis Foundation-commissioned survey |
| Clinic-Based | 0 | N/A |
| Insurer-Claims | 1 | 2003 MedStat MarketScan |
| Internet-Based | 1 | survey of physicians |
| Registry-Based | 1 | 2005 National Psoriasis Foundation survey |

Validity of the Data

The majority of the population-based literature on psoriasis and psoriatic arthritis severity utilizes data from a 2001 National Psoriasis Foundation survey. More research is needed to validate these results.

PASI has been validated for research purposes, though it's less practical in a clinical setting. SAPASI is moderately validated, and % BSA is helpful from a practical standpoint, but if the lesions are small, then this method becomes more difficult to use.

Needs and Gaps

- More research on severity in the US adult population with psoriasis
- More research on severity in the US adult population with psoriatic arthritis
- More research on severity of psoriasis in the US pediatric population
- More research on severity of psoriatic arthritis in the US pediatric population
- A determination of what should be evaluated in terms of severity for psoriatic arthritis
- Validation study for prospective measures of severity
- Evaluation of the validity of severity assessments by general practitioners

- Severity should incorporate QOL, function, and other elements of burden
- A tool that can be used to evaluate severity from a population-based standpoint
- Estimates of the prevalence of psoriasis at varying levels of severity
- Estimates of the prevalence of psoriatic arthritis at varying levels of severity

Databases Used

- Insurer claims datasets (IMS Health Integrated Administrative Claims, Medstat MarketScan, Medstat)
- John's Hopkins internet-based survey
- National Health and Nutrition Examination Survey (NHANES)
- National Health and Wellness Survey (NHWS)
- National Psoriasis Foundation surveys
- Psoriasis Quality of Life study

Tools Used to Measure Severity

- Physician Global Assessment (PGA)
- Lattice System Physician's Global Assessment (LS-PGA)
- % Body Surface Area (BSA)
- Number of palms of coverage
- Patient Report of Extent of Ps Involvement (PREPI)
- Ps Area Severity Index (PASI)
- Self-administered Ps Area Severity Index (SAPASI)

### 2.3.10 Cardiovascular disease as a comorbidity

The following summarizes the US-based literature for cardiovascular disease as a comorbidity (Tables 25-26), examines the validity of the data, and identifies needs, gaps, and databases used to study the issue.

**Table 25: Cardiovascular disease as a comorbidity – psoriasis research**

| Article Type | n | Data Source |
|---|---|---|
| Population-Based | 1 | 1991-2005 Nurses' Health Study II |
| Clinic-Based | 5 | Various clinic sites across the US |
| Insurer-Claims | 5 | 2003 Medstat and 1998-2005 unspecified database (n=1)<br>2003 MedStat MarketScan (n=1)<br>2001-2002 IMS Health Integrated Claims and 2001-2002 MarketScan (n=1)<br>1996-2000 MedStat (n=1)<br>1996-2000 MarketScan and Medicare Supplemental COB (n=1) |
| Internet-Based | 1 | 2004 National Health and Wellness Survey |
| Registry-Based | 1 | 2005 National Psoriasis Foundation survey |

**Table 26: Cardiovascular disease as a comorbidity – psoriatic arthritis research**

| Article Type | n | Data Source |
|---|---|---|
| Population-Based | 0 | N/A |

| | | |
|---|---|---|
| Clinic-Based | 0 | N/A |
| Insurer-Claims | 1 | 2001-2002 PharMetrics Patient-Centric Database |
| Internet-Based | 0 | N/A |
| Registry-Based | 1 | 2005 National Psoriasis Foundation survey |

Validity of the Data

Although several clinic-based studies have found an association with a variety of cardiovascular diseases, only one population-based study has been conducted for psoriasis. No US population-based research has examined the relationship with psoriatic arthritis. As a result, we are unable to evaluate the validity of the data at this time.

Needs and Gaps

- More population-based research on relationship with cardiovascular disease

Databases Used

- Insurer claims (IMS Health Integrated Claims, Medstat, MarketScan, Medicare Supplemental Coordination of Benefits, PharMetrics Patient-Centric Database)
- Nurses' Health Study II
- National Health Interview Survey (NHIS)
- National Health and Nutrition Examination Survey (NHANES)
- National Health and Wellness Survey
- National Psoriasis Foundation surveys

### 2.3.11 Obesity as a comorbidity

The following summarizes the US-based literature for obesity as a comorbidity (Tables 27-28), examines the validity of the data, and identifies needs, gaps, and databases used to study the issue.

**Table 27: Obesity as a comorbidity – psoriasis research**

| Article Type | n | Data Source |
|---|---|---|
| Population-Based | 3 | 2000 MEPS/1992-2000 MCBS (n=1)<br>1991-2005 Nurses' Health Study II (n=2) |
| Clinic-Based | 4 | Various clinic sites across the US |
| Insurer-Claims | 2 | 2003 MedStat MarketScan (n=1)<br>1996-2000 MedStat (n=1) |
| Internet-Based | 0 | N/A |
| Registry-Based | 0 | N/A |

**Table 28: Obesity as a comorbidity – psoriatic arthritis research**

| Article Type | n | Data Source |
|---|---|---|
| Population-Based | 0 | N/A |
| Clinic-Based | 1 | Utah |
| Insurer-Claims | 0 | N/A |

| | | |
|---|---|---|
| Internet-Based | 0 | N/A |
| Registry-Based | 0 | N/A |

Validity of the Data

There have been surprisingly few US-based studies examining this relationship, and one of the three population-based studies on the issue lacked the power to accurately evaluate this relationship. The paucity of information related to obesity and psoriatic arthritis precludes an evaluation of the validity of the data.

Needs and Gaps

- More population-based research examining the association between psoriasis and obesity
- Population-based research examining the association between psoriatic arthritis and obesity to supplement the clinic-based findings

Databases Used

- Insurer claims (MedStat, MedStat MarketScan)
- Medical Expenditure Panel Survey (MEPS)
- Medicare Current Beneficiary Survey (MCBS)
- Nurses' Health Study II

### 2.3.12 Natural History

The following summarizes the US-based literature for natural history (Tables 29-30), examines the validity of the data, and identifies needs, gaps, and databases used to study the issue.

**Table 29: Natural history – psoriasis research**

| | n | Data Source |
|---|---|---|
| Population-Based | 2 | 2001 National Psoriasis Foundation-commissioned survey (n=1)<br>1991 Psoriasis Quality of Life study (n=1) |
| Clinic-Based | 5 | Various clinic sites across the US |
| Insurer-Claims | 0 | N/A |
| Internet-Based | 0 | N/A |
| Registry-Based | 0 | N/A |

**Table 30: Natural history – psoriatic arthritis research**

| Article Type | n | Data Source |
|---|---|---|
| Population-Based | 3 | 2001 National Psoriasis Foundation-commissioned survey (n=1)<br>1970-1999 Rochester Epidemiology Project (n=1)<br>1982-1991 Rochester Epidemiology Project (n=1) |
| Clinic-Based | 2 | Various clinic sites across the US |
| Insurer-Claims | 0 | N/A |
| Internet-Based | 0 | N/A |
| Registry-Based | 0 | N/A |

Validity of the Data

The most current population-based data for psoriasis and psoriatic arthritis was a 2001 National Psoriasis Foundation-commissioned survey. More research should be conducted to validate these results as well as those of the studies conducted in Olmstead County (Rochester Epidemiology Project).

Needs and Gaps

- Population-based research examining natural history of psoriasis and psoriatic arthritis
- More information on acute episodes and flares in terms of prognosis, remission, etc.
- More information on the relationship between psoriasis onset and infections
- More information on the natural history of psoriasis at various levels of severity
- More information on the natural history of psoriatic arthritis overall

Databases Used

- National Psoriasis Foundation-commissioned survey
- Psoriasis Quality of Life study
- Rochester Epidemiology Project

## 2.4 *Public Health Agenda*

Based on the six public health issues identified during the expert consultation, a Public Health Agenda was developed that identified 11 topics and relevant specifics (Table 31). Unless otherwise specified, this Agenda is for population-based research in the United States and applies to both psoriasis and psoriatic arthritis.

**Table 31: Public Health Agenda**

| Topic | Specifics |
|---|---|
| Case Definitions | • Validation study to determine the best public health surveillance case definitions<br>• Examine potential to use existing psoriatic arthritis screening tools |
| Prevalence and Disparities | • Update prevalence estimates with most recent data available<br>• Examine prevalence at all levels of severity<br>• Examine disparities (e.g., age, gender, racial/ethnic)<br>• Define the prevalence and characteristics of those with undiagnosed psoriasis<br>• Estimate the prevalence of psoriatic arthritis within the general population and within the psoriasis population |
| Severity | • Examine disease severity in the pediatric population<br>• Examine disease severity in the adult population<br>• Determine the best measures of disease severity for population-based studies |
| Cost | • Update direct cost estimates with the most recent data<br>• Update indirect cost estimates with the most recent data<br>• Examine the relationship between cost and disease severity |
| Employment/ Ability to Work | • Examine the impact on employment and/or ability to work<br>• Determine if the diseases affect income and health insurance coverage |
| Health Care | • Examine health care utilization |

| | |
|---|---|
| Utilization | |
| Health-related Quality of Life (HRQOL) | • Identify to the most appropriate HRQOL measures<br>• Update current HRQOL estimates with the most recent data<br>• Examine disparities in HRQOL<br>• Examine relationship with disease severity |
| Age of Onset | • Update estimates of age of onset with most recent data<br>• Determine the best instrument to reduce recall bias for age of onset |
| Natural History | • Examine psoriasis progression at levels of disease severity<br>• Examine the role of infection in the onset of psoriasis<br>• Examine psoriasis recurrence and remission<br>• Examine the natural history of psoriatic arthritis |
| Comorbidity: Cardiovascular Disease (CVD) | • Examine the relationship with CVD's and CVD mortality<br>• Examine the relationship between psoriatic arthritis treatment and CVD |
| Comorbidity: Obesity | • Examine the relationship with obesity<br>• Examine the relationship between the psychosocial impact of these conditions and obesity |

## 2.5 *Priorities for Public Health Research*

Within the Public Health Agenda, a list of priorities that could be undertaken as time, opportunity, and resources permit was generated (Table 32).

**Table 32: Priorities for Public Health Research**

| | |
|---|---|
| Priority 1 | **Case Definitions for Population-based Research**<br>• Validity of psoriasis case definitions for US, population-based studies<br>• Validity of psoriatic arthritis case definitions for US, population-based studies |
| Priority 2 | **Prevalence, Disparities, and Comorbidities**<br>• Prevalence of psoriasis by age, gender, race/ethnicity, and age of onset<br>• Prevalence of psoriatic arthritis by age, gender, race/ethnicity, and age of onset<br>• Prevalence of obesity in the psoriasis population<br>• Prevalence of obesity in the psoriatic arthritis population<br>• Prevalence of cardiovascular diseases in the psoriasis population<br>• Prevalence of cardiovascular diseases in psoriatic arthritis population |
| Priority 3 | **Health Care Utilization, Work, Costs**<br>• Health care utilization in the psoriasis population<br>• Health care utilization in the psoriatic arthritis population<br>• Employment and/or work burden associated with psoriasis<br>• Employment and/or work burden associated with psoriatic arthritis<br>• Direct costs of psoriasis<br>• Direct costs of psoriatic arthritis<br>• Indirect costs of psoriasis<br>• Indirect costs of psoriatic arthritis |
| Priority 4 | **Quality of Life, Severity, Natural History**<br>• Impact of psoriasis on HRQOL<br>• Impact of psoriatic arthritis on HRQOL<br>• Prevalence of psoriasis at varying levels of severity<br>• Relationship between HRQOL and psoriasis severity |

# 3 Addressing Psoriasis & Psoriatic Arthritis from a Public Health Perspective

The second phase of the project began in September 2010 and will continue through September 2012. To date, this work has included an in-depth review of the public health case definitions used for psoriasis and psoriatic arthritis (Section 3.1), epidemiologic analyses using existing population-based data sources in the US (Section 3.2), and the initiation of a case definition validation study (Section 3.3). This phase will be concluded with a meeting of experts to discuss next steps in developing the public health agenda (Section 3.4).

## 3.1 *Literature Review: Case Definitions and Screening Tools*

The existing literature retrieved from the first phase was abstracted into a Microsoft Excel spreadsheet according to the following convention:

- Definition (exact language used and any related restrictions)
- Source of definition
- Validity (construct, content, criterion, sensitivity, specificity, predictive value)
- Reliability of the case definition

Psoriasis was more frequently defined in the methods of US articles; however, psoriatic arthritis was more frequently defined in the methods of non-US articles. Very few articles addressed psoriasis or psoriatic arthritis case definitions in their results (Table 33).

**Table 33: Number of articles that reported case definition used**

| | Psoriasis | | Psoriatic Arthritis | |
|---|---|---|---|---|
| Article Section | US articles (n=68) | non-US articles (n=130) | US articles (n=68) | non-US articles (n=130) |
| Introduction | 35 | 42 | 14 | 48 |
| Methods | 34 | 48 | 26 | 51 |
| Results | 5 | 6 | 8 | 15 |

NOTE: case definitions may have been discussed in multiple sections; therefore, the numbers will not total 68 for US articles or 130 for non-US articles.

### 3.1.1 Psoriasis Case Definitions and Screening Tools

Case Definitions in the Literature

- Common terms: “chronic”, “inflammatory”, “systemic”, “autoimmune”, “immune-mediated”
- Population-based studies primarily use codes (e.g., ICD-9) and self-report
- Canadian and European literature mirrors US case definitions.

Gap - no uniform case definition for epidemiologic studies

- *Griffiths et al., 2007, page 265*: “Accurate figures for the prevalence of psoriasis are difficult to obtain because of an absence of validated diagnostic criteria.”
- *Naldi et al., 2004, page 121:* “…up to now, no widely employed diagnostic criteria have been developed for clinical and population-based studies of psoriasis. This is a significant

problem in view of the existence of borderline or indeterminate cases besides the more obvious ones."

Gold Standard Case Definition

- Dermatologist-diagnosed psoriasis

Screening Tools

The Psoriasis Screening Tool (PST) is a one page, eight-item, self-administered questionnaire that was developed to validate self-report psoriasis in epidemiologic studies. The tool was tested in an ambulatory care setting and requires further validation in a larger, remote population (Dominguez et al., 2009).

### 3.1.2 Psoriatic Arthritis Case Definitions and Screening Tools

Case Definitions in the Literature

- Common terms: "chronic", "inflammatory", "seronegative"
- Classification Criteria for Psoriatic Arthritis (CASPAR) (2006), Fournie et al. (1999), McGonagle et al. (1999), ESSG (1991), Gladman et al. (1987), Vasey & Espinoza (1984), Bennett et al. (1979), Moll & Wright (1973)
- Juvenile psoriatic arthritis: Vancouver, Durban, Lambert

Gap - no uniform, validated case definition for epidemiologic studies

- *Chandran et al., 2010, page J316:* "There are a number of challenges in conducting epidemiological studies in psoriatic arthritis. The most important problem was lack of validated classification criteria."
- *Wilson et al., 2009, page J361:* "Several…criteria with widely variable sensitivity and specificity have been used, but none have been universally accepted. Hence, the comparability of the published incidence and prevalence estimates of psoriatic arthritis is problematic."
- *Symmons et al., 2006, page 552:* "The study of the epidemiology, treatment, and prognosis of psoriatic arthritis is severely hampered because there is no widely accepted, validated case definition. The absence of an accepted case definition is, in part, due to controversy about the nature and even existence of psoriatic arthritis."

Gold Standard Case Definition

- Rheumatologist-diagnosed psoriatic arthritis using CASPAR criteria

Screening Tools

To date, four screening tools have been developed and tested in a variety of settings. The Psoriatic Arthritis Screening and Evaluation (PASE) is a 15-item questionnaire developed in the US to screen individuals with psoriasis for symptoms of inflammatory arthritis. It has been

validated in a dermatology clinic, an arthritis clinic, and a combined dermatology-rheumatology clinic (Husni et al., 2007; Dominguez et al., 2009).

The Toronto Psoriatic Arthritis Screening tool (ToPAS) is a 12-item questionnaire that was developed in Canada and has been validated in a variety of settings (Gladman et al., 2009c). It has not yet been validated in the US. The Psoriasis Epidemiology Project (PEST) was developed in the United Kingdom and based on the previously developed Psoriatic Arthritis Questionnaire (PAQ) (Qureshi et al., 2008).

## 3.2 *Epidemiologic Studies using Existing Data Sets*

### 3.2.1 Data Set Review

In preparation for the epidemiologic research, a review of existing population-based data sources in the US was undertaken. NHANES and NHIS use self-reported psoriasis or psoriatic arthritis as their case definition; the remaining data sets use ICD-9 codes. Of the 13 data sets, seven are publicly available for free (Table 34).

**Table 34: Population-Based Data Sets for Studying Psoriasis and Psoriatic Arthritis**

| Data Set | Acronym | Case Definition | Access |
|---|---|---|---|
| National Health and Nutrition Examination Survey | NHANES | Self-report | Public, CDC |
| National Health Interview Survey* | NHIS | Self-report | Public, CDC |
| National Ambulatory Medical Care Survey | NAMCS | ICD-9 code | Public, CDC |
| National Hospital Ambulatory Medical Care Survey | NHAMCS | ICD-9 code | Public, CDC |
| National Hospital Discharge Survey | NHDS | ICD-9 code | Public, CDC |
| Medicare Standard Analytic Files | Medicare SAF | ICD-9 code | Public, CMS |
| Medical Expenditure Panel Survey** | MEPS | ICD-9 code | Public, AHRQ |
| Nationwide Inpatient Sample | NIS | ICD-9 code | Purchase, AHRQ |
| Kids' Inpatient Database | KID | ICD-9 code | Purchase, AHRQ |
| Nationwide Emergency Department Sample | NEDS | ICD-9 code | Purchase, AHRQ |
| State Inpatient Databases | SID | ICD-9 code | Purchase, AHRQ |
| State Ambulatory Surgery Databases | SASD | ICD-9 code | Purchase, AHRQ |
| State Emergency Department Databases | SEDD | ICD-9 code | Purchase, AHRQ |

CDC: Centers for Disease Control and Prevention; AHRQ: Agency for Health Research and Quality

*NHIS asks about psoriasis and eczema in the same question, which prevents differentiating psoriasis from eczema in the results. NHIS does not ask about psoriatic arthritis.

**MEPS uses the first three digits of the ICD code, which prevents differentiating psoriasis (ICD-9-CM 696.1) from psoriatic arthritis (ICD-9-CM 696.0).

The Behavioral Risk Factor Surveillance Survey (BRFSS), Health and Retirement Study (HRS), and State and Local Integrated Telephone Survey (SLAITS) were reviewed but do not include information on psoriasis or psoriatic arthritis. Though not population-based, the MarketScan Research Database was found to contain a large amount of information on healthcare practices and costs for the working population and their dependents. This would likely be a useful source for monitoring psoriasis and psoriatic arthritis. Access to the databases must be requested and purchased.

The utility of each data source will depend on the condition of interest and research objective (e.g., surveillance, disparities, quality of life). There are options for population-based surveillance, studies into the economic impact of these diseases, and sufficient demographic data to assess potential health disparities. However, available data sources are more limited in their utility for investigating etiology.

Based on the results of the data set review, the current work focused on four of the publicly available data sets: NHANES, NAMCS, NHAMCS, and NHDS.

### 3.2.2 NHANES study

The *Priority 2* (prevalence, disparities, and comorbidities) and *Priority 4* (severity and quality of life) research needs were addressed through a study of NHANES data. NHANES is an on-going, population-based survey that studies the health and nutritional status of individuals in the US. A key advantage of this survey is its combination of interviews with physical examination, laboratory, and prescription drug use data. The interview component of NHANES addresses demographic, socioeconomic, dietary, and health-related issues. The mobile examination center (MEC) provides physical examination and laboratory components (CDC, 2009a).

Although NHANES has been administered annually since 1999, psoriasis was included from 2003-2006 and then again starting in 2009. Due to the small number of psoriasis data, the current study includes the 2003-2004, 2005-2006, and 2009-2010 NHANES interview and mobile examination center (MEC) data. The psoriasis case definition included participants who responded "yes" to the question, "Have you ever been told by a health care provider that you had psoriasis?"

### 3.2.3 NAMCS-NHAMCS Prevalence Study

The *Priority 2* research needs were further addressed through a NAMCS-NHAMCS study of prevalence and disparities. NAMCS is an on-going, national survey of ambulatory medical care delivery that has been conducted annually since 1989. It is based on a sample of visits made to non-federal, office-based physicians and excludes anesthesiologists, pathologists, and radiologists (CDC, 2009b). NHAMCS was initiated in 1992 to complement NAMCS and was based on a sample of visits to outpatient departments (OPDs) and emergency departments (EDs) in non-federal, non-institutional, general, and short-stay hospitals (CDC, 2009c). The NHAMCS-OPD component is almost identical to NAMCS, and results have often been combined. The NHAMCS-ED data includes general, adult, pediatric, fast track, psychiatric, and trauma.

The NHAMCS-ED data were excluded from the analysis because the information on the number of visits in the last 12 months (which is key to the conversion of visits to prevalence information) was only available from 2007-2009, and it was not imputed and over 40% of the data on the past visit variable was missing. Therefore, the current study included 2004-2009 NAMCS and NHAMCS-OPD data using ICD-9-CM codes 696.0 (psoriatic arthropathy) and 696.1 (other psoriasis and similar disorders). An advantage of this data set was that the prevalence of psoriasis and psoriatic arthritis in the ambulatory health care system could be estimated.

To allow for a more complete ascertainment of those visits with potential psoriasis patients, the broad definition of psoriasis (ICD-9-CM 696.1 *or* 696.0) was used. To examine the degree of underestimation of psoriasis, additional analyses were carried out that restricted the psoriasis code to ICD-9-CM 696.1. Psoriatic arthritis was analyzed using ICD-9-CM code 696.0.

### 3.2.4 NAMCS-NHAMCS-NHDS Health Care Utilization Study

Health care utilization was addressed through a study using the NAMCS, NHAMCS-OPD and NHDS data sets. The NHAMCS-ED data were excluded due to differences in the information that is collected on health care utilization. Additionally, the number of cases that the NHAMCS-ED data would have added for psoriasis is quite small and it would not have added any psoriatic arthritis cases.

NHDS was an on-going national probability survey of inpatients discharged from non-federal, non-institutional short-stay hospitals. The NAMCS and NHAMCS-OPD data sets were analyzed together; however, psoriatic arthritis was excluded due to its small sample size. The NHDS data set was analyzed separately from NAMCS and NHAMCS-OPD and included both psoriasis and psoriatic arthritis.

At the time of analysis, the most recent data available for both surveys was 2009; therefore, the current study includes 2004-2009 NAMCS, NHAMCS-OPD, and NHDS data using ICD-9-CM codes 696.0 (psoriatic arthropathy) and 696.1 (other psoriasis and similar disorders).

## 3.3 *Case Definition Validation Study*

During the 2010 expert consultation, one of the main issues that arose was the need to better define psoriasis and psoriatic arthritis for public health purposes. Existing case definitions have used self-report and ICD codes; however, a surveillance system based on self-report is nonviable because of the absence of validated questions in existing surveys, the relative rarity of the conditions which requires collecting and analyzing multiple years of data, and constrained space in ongoing surveys.

With the move toward electronic health records, health care system-based surveys offer practical advantages for maintaining surveillance because they include physician-assigned ICD-9 codes, offer reasonable timeliness, and with some mathematical manipulation, can provide prevalence estimates in the ambulatory health care system. Since these surveys are visit-based rather than patient-based, two methodological issues need to be addressed to consider their use in national surveillance: 1) what is the likelihood the diagnosis is correct and 2) what is the likelihood that a patient with psoriasis or psoriatic arthritis has their condition reflected in their visit codes (e.g., visits for an unrelated problem like influenza).

To date, three studies have explored the validity of health care system recorded ICD-9 codes for psoriasis (Icen et al., 2008) or psoriatic arthritis (Singh et al., 2007; Love et al., 2011) in the adult population aged 18 years or older. Icen et al. (2008) used the unique Mayo Clinic population in Olmstead County, Minnesota; therefore, these findings may not be generalizable to other health systems or the general population. Singh et al. (2007) conducted their research in the Veterans Affairs health system, which is excluded from nationally-representative surveys such as NAMCS

or NHAMCS. Finally, Love et al. (2011) focused primarily on validating an algorithm rather than ICD-9 codes. As such, none of these studies help address the issue of whether a NAMCS- or NHAMCS-based surveillance of psoriasis or psoriatic arthritis might be based on valid diagnostic data.

Since the validity of ICD-9-CM based case definitions could not be addressed using existing, population-based data, CDC is funding a validation study with a health maintenance organization (HMO) population to determine the validity of using ICD-9-CM based case definitions for psoriasis and psoriatic arthritis surveillance.

# 4 Next Steps

Both psoriasis and psoriatic arthritis present a substantial public health burden; however, additional, population-based research is required in all six of the priority areas (burden, case definitions, comorbidities, disparities, natural history, and severity). In particular, research is needed to analyze the following:

- Age of onset
- Cardiovascular disease as a comorbidity
- Employment and/or work-related burden
- Direct and indirect costs
- Natural history

Other areas that would be beneficial to examine from a public health perspective include:

- Burden of disease in the pediatric population
- Prescription drug use
- Treatment and control

CDC has begun to address the public health agenda for assessment of psoriasis and psoriatic arthritis through its public health research on a subset of the research needs. To successfully address all issues identified during the expert consultation, the engagement of the larger dermatologic and public health communities is needed and welcomed.

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